INDIAN JOURNAL OF MEDICAL ETHICS

Selected readings 1993-2003

Forum for Medical Ethics Society, Mumbai
and
Centre for Studies in Ethics and Rights, Mumbai

Editorial collective
Neha Madhiwalla, Bashir Mamdani, Meenal Mamdani,
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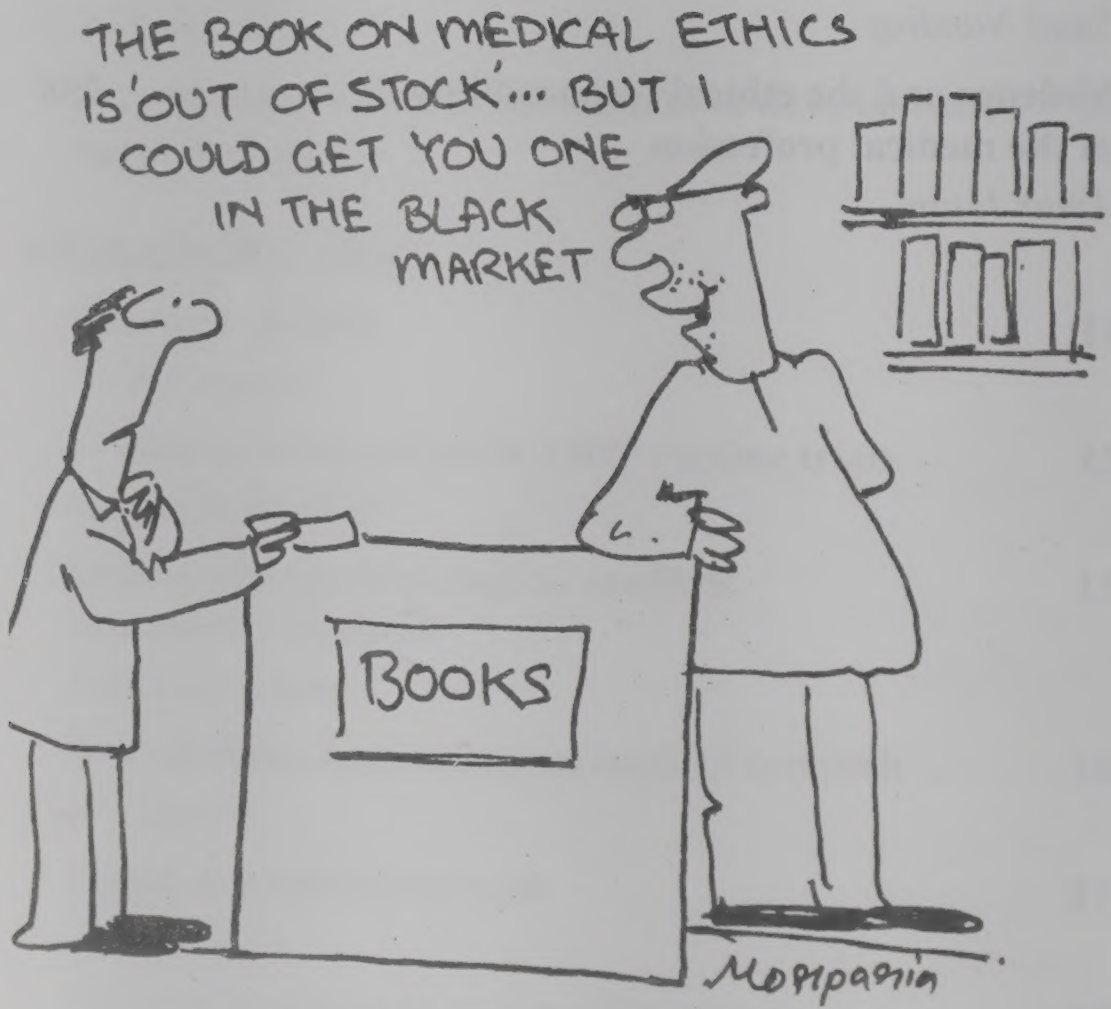
THE BOOK ON MEDICAL ETHICS IS OUT OF STOCK... BUT I COULD GET YOU ONE IN THE BLACK MARKET
BOOKS

Introduction

"Life is short, and Art long; the crisis fleeting; experience perilous, and decision difficult. The physician must not only be prepared to do what is right himself, but also to make the patient, the attendants,and externals cooperate."

– Hippocrates


JUST TAKE IT EASY, AT MY HOSPITAL, ONLY DISPOSABLES ARE USED
HOSPITAL
ETHICS
PRINCIPLE
SCRUPLES
HONESTY

Preface

This story begins with a failure. Thirteen years ago a group of doctors fought the Maharashtra state medical council elections on the platform of 'ethical medical practice'. They lost, and they lost badly. But instead of conceding defeat they turned that loss into a gain. They started a newsletter where people with a commitment to ethics could express their views, and thus promote better medical practice. That newsletter eventually became *Indian Journal of Medical Ethics*.

This selection of articles from the first 10 years of the journal provides a glimpse into concerns and debates in medical ethics in a decade that saw the beginning of turbulent times for health care in India.

The 1990s witnessed a marked expansion in private health care services in the country. This trend dates back to earlier decades but has been accentuated in recent years. Advances in medical technology have been exploited by the private sector. Health care costs have spiralled. As private medical colleges mushroom, the doctors of today will also have invested lakhs of rupees on their education – all of which must be recovered soon after graduation. None of this brings us closer to the ideal of accessible and affordable health care for all.

Simultaneously, the pharmaceutical industry has intensified its efforts to influence the medical profession. Thousands of similar but non-essential and even irrational and dangerous drugs compete for shelf space in pharmacies. Doctors are updated on new developments by medical representatives, not medical journals. Pharmaceutical sponsorship of medical conferences has now been institutionalised. The doctor-drug company relationship threatens the doctor-patient relationship.

Health care in India today is dominated by allopathic medicine despite the existence of centuries-old systems such as ayurveda and unani, or the more recent homoeopathy, all of which seem to treat the patient in a more holistic manner. Indeed, as the introductory articles to this selection show, the dilemmas of contemporary medicine are addressed in the works of Charaka and

Hippocrates. However, today the interaction between these systems and the dominant allopathy creates its own set of problems.

High-tech hazards

Western medical technology has steered doctors away from simpler approaches to more complex ones. In many areas, such as end-of-life care, it has created new dilemmas. And in fields such as organ transplant and prenatal diagnosis, the profession has used the technology for personal profit rather than social good.

We also face situations that have little or nothing to do with technology: epidemics, earthquakes and tidal waves highlight the inadequate role played by health professionals in humanitarian emergencies; state-sponsored violence and communal riots force the profession to confront its responsibilities – and culpability – in these situations. The provider-patient relationship is particularly complicated in other, ongoing, crises such as the HIV epidemic and its fallout.

While most of our attention has been focussed on clinical practice, research ethics is a growing concern. India is becoming fertile testing ground for researchers from abroad. With a billion-strong population and poor regulation, it is an ideal place to experiment with new medical products. And if biomedical research can put participants at physical risk, the expansion in social science research in health poses questions of a different kind of harm.

The medical profession and its discontents

Over the last decade patients and their relatives have become increasingly dissatisfied with their experiences of health services, and increasingly distrustful of the medical profession. Medical councils have done a poor job of ensuring ethical behaviour by doctors. Indeed, corruption controversies seem to be their only claim to fame. The medical associations have protected neither doctors nor patients. As patients turned to the law, including the Consumer Protection Act, it has resulted in the practice of 'defensive medicine'. The profession is apparently insecure in what it sees as a fight for its own survival. Not surprisingly, most cases registered under the CPA were instigated by doctors against other doctors. It is rare to find patients suing doctors on their own.

Doctors in India as a community have traditionally stayed away from social issues. They have rarely taken a stand on larger issues like self-regulation within the profession, the need for relevant research, the impact of infrastructure inadequacies and drug shortages, and so on.

There are, however, some who have consistently spoken out against the wrongs in the profession. Most of them are medical professionals, but researchers, activists, and even the common man have expressed the need for introspection within the medical profession.

Selected views

Indian Journal of Medical Ethics – formerly *Issues in Medical Ethics* – has been instrumental in keeping this voice alive through the past decade. Most of the contributors to this anthology are practising physicians and represent a small but vocal minority within the profession. They speak of the dilemmas faced by health care providers on a daily basis in India. Some also look at efforts at resolving these dilemmas. Some of these articles discuss questions of personal ethical integrity. Others refer to the interactions amongst health professionals, and between them and patients. And almost all of them also touch upon the choices posed by high technology and limited resources in a poor society, raising questions of equity and justice.

The articles here were chosen because they best articulated the major concerns discussed within the journal over these years. Practically all of them refer to problems specific to India and other developing countries where health care professionals work for people whose access to care is limited by their poverty, lack of education and the traditional reverence for doctors. They are also limited by an inaccessible health care system.

Some writers refer to ethics indirectly, as they look at the relevance of technology-driven medicine in a poor country such as India. Some essays have been included specifically because they discuss key controversies from different but important perspectives.

It was difficult to choose just 29 articles from the many essays, reports, narratives and commentaries published in the journal. We

hope that readers of this selection will be provoked into going through back issues of the journal where the battles of medical ethics are narrated in more detail. The last 13 years have produced an extensive documentation of issues and controversies in India. Corruption in the profession continues to be a matter of concern, and the need to focus on personal integrity is as important today as it was in the first issue of the journal. But we are also viewing health care ethics in the larger context of global changes in the health sector, the decline of the public sector, the accelerated development of corporate hospitals, the politics of population control and contraceptive research, the rise in inequities, an increase in conflict and fundamentalism and so on. It is from this perspective that we are beginning to address the ongoing ethical challenges in health care.

The Hippocratic Oath updated

Eugene D Robin

Over the years, IJME *has published a number of oaths and codes of medical ethics, from the Hippocratic Oath to Charaka's oath of initiation, to the Islamic and Jewish codes and most recently the Code of Medical Ethics of the Medical Council of India. This adaptation of an updated version of the Hippocratic Oath was published in* BMJ, *July 9, 1994.*

In the name of suffering humanity; with humility, compassion and dedication to the welfare of the sick according to the best of my ability and judgement; I will keep this oath.

I will be honest with my patients in all medical matters. When this honesty reveals bad news I will deliver it with sympathy, understanding and tact.

I will attempt to provide whatever information my patients need so that I can care for them more effectively.

I will provide my patients with acceptable alternatives in diagnosis, medical and surgical treatment, explaining the risks and benefits of each alternative as best as I know them.

I will encourage my patients to seek medical opinions other than my own before accepting that offered by me.

I will allow my patients to make the ultimate decision about their own care. When they are incapable of making decisions, I will accept the decision of their family members or loved ones, encouraging these surrogates to decide as they believe the patient would have decided.

I will provide care to all patients regardless of sex, race, creed, sexual preference, lifestyle or economic status. In particular, I will volunteer some of my time to providing free care to the poor, the homeless, the disadvantaged, the dispossessed and the helpless.

I will not sit in moral judgement on any patient but will treat the illness to the best of my ability regardless of the circumstances. I will be empathetic to patients suffering from illnesses caused by alcohol, drugs or other forms of self-abuse.

I will turn away no patient, even those with dreaded, contagious diseases like AIDS.

Knowing my own inadequacies and those of medicine generally, I will strive to cure when possible, relieve and comfort always.

I shall perform medical tests only if there is a reasonable chance that the results will improve the outcome for my patients. I will not perform any tests or procedures or surgery solely to make money.

I will freely refer my patients to other physicians if I am convinced that their treatment is better than mine.

I will freely furnish copies of medical records to the patient or, when authorised by the patient, to the family, upon request. I will do unto patients and their families only what I would want done unto me or my family. I will not experiment upon patients unless they give truly informed consent. I will strive to instruct patients fully so that truly informed consent is possible.

I will remain a student all my professional life, attempting to learn not only from formal medical sources but from my patients as well. I will apply the lessons they provide to the care of other patients.

I will treat my professional colleagues with respect and honour; but I will not hesitate to testify openly about physicians and medical institutions that are guilty of malpractice, malfeasance, cupidity or fraud.

I will defend with equal fervour colleagues who are unjustly accused of malpractice, malfeasance, cupidity or fraud.

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INCENTIVE CARE PVT. LTD.
THEY ARE TRULY OPEN ABOUT KICK-BACKS!
Manpasia

Medical ethics in India: ancient and modern

C M Francis

In this essay a medical teacher and ethicist contrasts the primacy of autonomy in the western tradition with the primacy of collective decision-making in the Indian tradition. The writer is concerned less with doctors' actions than their character. He sees the professional and personal lives of a doctor as one. He links ethics as discussed in the Indian texts to current issues such as abortion, euthanasia and sex selection. This essay is the starting point for further discussions on issues such as the relevance of ancient teachings today. It is also worth noting that the neglect of Indian systems of medicine has resulted in little research and innovation in indigenous systems, both in their practice and in the development of the philosophy behind it.

Introduction

Ancient Indian thought, philosophy and ethics, developed with a rational synthesis and went on gathering into itself, new concepts. Spiritual experience was the foundation of India's cultural history. Next to spirituality, *dharma* (ethical conduct according to one's state) was the most important concept of Indian thought. Both are, unfortunately, on the decline.

With the coming of the Europeans and, especially during colonial rule, imitation of what the rulers did and practised became more and more popular. But there was also resistance to this wholesale copying of the foreigners' practices. "Reverence for the past is a national trait. There is a certain doggedness of temperament, a stubborn loyalty to lose nothing in the long march of the ages. When confronted with new culture or sudden extensions of knowledge, the Indian does not yield to the temptations of the hour but holds fast to his traditional faith, importing as much as possible

of the new into the old. Conservative liberalism is the secret of the success of India's culture and civilization." (1)

The value systems in India have been influenced by all the religions, but mostly by Hinduism, the major religion (82.64 per cent of the population), contributing to the philosophy and ethics of the people of the country. The fundamental basis of ethics arises from the Hindu belief that we are all part of the divine *paramatman*; we have in each of us *atman,* part of that *paramatman.*

The ultimate aim is for our *atman* to coalesce with *parmatman* or *brahman* to become one. According to the Vedas (4000 BC to 1000 BC), the call to love your neighbour as yourself is "because thy neighbour is in truth thy very self and what separates you from him is mere illusion." Closely allied to Hinduism are Jainism and Buddhism. These religions proclaim *ahimsa paramo dharma.* Most important of all our actions is *ahimsa*, non-violence. Patanjali defined *ahimsa* as *Sarvatha sarvada sarvabutanam anabhidroha* (1), a complete absence of ill-will to all beings.

Ayurveda is the ancient science of life. It lays down the principles of management in health and disease and the code of conduct for the physician. Charaka has described the objective of medicine as two fold: preservation of good health and combating disease (2). Ayurveda emphasised the need for a healthy lifestyle; cleanliness and purity, good diet, proper behaviour, and mental and physical discipline. Purity and cleanliness were to be observed in everything: *jalasuddi* (pure water), *aharasuddi* (clean food), *dehasuddi* (clean body), *manasuddi* (pure mind) and *desasuddi* (clean environment).

Ayurveda calls upon the physician to treat the patient as a whole: "*Dividho jayate vyadih, Sariro manasasthatha, Parasparanz tavorjanma, Nirdvadvam nopalabhyate.*" (Diseases occur both physically and mentally and even though each part might be dominant, they cannot be compartmentalised.) Ayurveda treats man as a whole body, mind and what is beyond mind. The earliest protagonists of Indian medicine, such as Atreya, Kashyapa, Bhela, Charaka and Susruta have based their writings on the foundations of spiritual philosophy and ethics. But the one teacher of Ayurveda who established the science on the foundation of spirituality and ethics was Vagbhata, the author of *Astanga Hridaya* (3). Vagbhata says, "*Sukarthah sarvabutanam, Matah sarvah pravarthayah,*

Sukham ca na vina dharmat, thasmad dharmaparo bhavet." (All activities of man are directed to the end of attaining happiness, whereas happiness is never achieved without righteousness. It is the bounden duty of man to be righteous in his action.)

Charaka Samhita prescribes an elaborate code of conduct. The medical profession has to be motivated by compassion for living beings (*bhuta-daya*) (4). Charaka's humanistic ideal becomes evident in his advice to the physicians. "He who practises not for money nor for caprice but out of compassion for living beings is the best among all physicians. Hard is it to find a conferrer of religious blessings comparable to the physician who snaps the snares of death for his patients. The physician who regards compassion for living beings as the highest religion fulfils his mission (*sidhartah*) and obtains the highest happiness."

Informed consent

There is a general belief among doctors in India that in a conflicting situation it is not possible to get informed consent because of rampant illiteracy. They believe that patients are unable to make a reasoned choice because they cannot appreciate the intricacies of alternative medical treatment, procedures or drug trials. Often a paternalistic view is taken: "The doctor knows best."

Dr Srinivasamurthy and colleagues (4) at the National Institute of Mental Health and Neurosciences, Bangalore, conducted a study into the relevance of obtaining informed consent. Almost all (99 per cent) of the subjects invited to participate in a drug trial were clear about whether or not to participate. Patients' level of understanding and decision-making related to the amount and quality of information provided. They did not correlate with social, economic, educational or other background characteristics.

Can the doctor withhold treatment, if there is no informed consent? Can a man refrain from benefiting from medical treatment and forfeit saving his life? Will the doctor be assisting suicide? On the contrary, does not the patient have the right to control what shall be done to his/ her body?

What is the status of informed consent when a patient is admitted to the hospital in a critical condition but in full possession of his/ her senses? Can the surgeon who diagnosed the condition requiring

immediate surgery refrain from operating on the sole ground that the patient had not given his/ her consent for the operation? If the patient later dies, what is the liability of the doctor?

An interesting case came up in the state of Kerala. A patient with acute abdominal pain was admitted to a district hospital. He was examined by the surgeon who diagnosed perforated appendix with general peritonitis, which required an immediate operation. But the operation was not performed by the surgeon and the patient died the next day. The relatives filed a petition in the court against the doctor personally and against the Kerala government vicariously. The doctor's defence was that the operation was not performed as the patient did not consent to it. The court rejected this plea and granted a decree against the doctor. The decision was confirmed by the Kerala High court in the appeal by the doctor. Two specialist surgeons who were called as expert witnesses stated that they would have operated on the patient without explicit consent.

In contrast is the view that every human being has a right to determine what shall be done with his or her own body. A surgeon who performs an operation without the patient's consent commits an assault for which he is liable (5). Indian physicians who are trained abroad or have imbibed this principle find themselves in a conflicting situation.

What is the ancient teaching in such circumstances? Charaka advises the physician to take into confidence the close relatives, the elders in the community and even the state officials before undertaking procedures which might end in the patient's death. The physician is then to proceed with the treatment.

In India, great trust is reposed in the doctor, but more and more people are questioning the practice. Trust based on the 'goodness' of the doctor is slowly giving way to the concept that making the decision is the right of the patient.

Control of fertility

The government of India and its people are concerned with the increase in population. One method proposed to control it is that of incentives and disincentives – incentives to those who subject themselves to sterilisation and disincentives to those who are not

willing to undergo sterilisation. Such discrimination raises an ethical issue. Why should a third or fourth child suffer from handicaps in education, nutrition, etc in comparison to other children? Educational and other facilities in the country are limited, especially in the villages. Discrimination in favour of one spells discrimination against another.

Right to life

Article 3 of the Universal Declaration of Human Rights states: "Everyone has the right to life, liberty and security of person." Article 6 states: "Everyone has the right to recognition as a person before law." The International Covenant on Civil and Political Rights (1966), Article 6, states: "Every human being has the inherent right to life." These and other declarations and affirmations raise the question: Who is this 'person' or 'human being'?

According to ancient Samkhya philosophy, there are two ultimate principles in the universe: *purusha* (soul) and *prkriti* (the body). The soul is immutable (*kutastha*) and imperishable (*nitya*) (6). The soul or *atman* descends into the zygote, produced from the union of the sperm and ovum. It is accompanied by the mind, which carries with it the influences of major actions done in previous states of existence. "Life starts with the union of the sperm and the ovum. Individuality is reckoned from that moment. It is at the moment of the sperm-ovum union that the transmigrating *atman*, *purusha* (the individual) gets his material encrustation, as dictated by his previous *karma.*" (Dr A Ramaswamy Iyengar, personal communication.)

Interventions on the new human being should be such as to maintain and improve the quality of life. Therapeutic procedures on the human embryo are licit if there is respect for life and integrity of the person (embryo/ foetus) and they do not involve disproportionate risk. The procedures must be directed towards healing, improvement in health and survival. The growing child in the womb cannot be considered as an object to be disposed of as thought fit by the mother or any other person.

What happens if an injury is caused to a foetus while in the uterus? Can damages be claimed? If the answer is yes, then the child is a person. Can the life of this person be ended by procedures approved

by others? It is sad that most doctors in India do not wish to concern themselves with this subject.

Abortion

Indian law allows abortion if the continuance of pregnancy would involve a risk to the life of the pregnant woman or grave injury to her physical or mental health.

Abortion was being practised earlier by many. Because it was illegal, it was practised in a clandestine manner. The passing of the Act made medical termination of pregnancy legal, with certain conditions for safeguarding the health of the mother.

From April 1972, Indian doctors have zealously performed abortions at the mother's request. Doctors advertise and invite women to have abortions done at their clinics. The government saw it as one more method of population control. Though abortion is legal, many find it immoral. Most physicians in India do not see anything unethical or immoral in carrying out medical termination of pregnancy within the first trimester, for the 'greater good' of the country in the light of the expanding population.

Abortion is severely condemned in vedic, upanishadic, the later *puranic* (old) and *smriti* literature.

Paragraph 3 of the Code of Ethics of the Medical Council of India says: "I will maintain the utmost respect for human life from the time of conception."

There is a conflict of the rights of two persons: the mother and the growing foetus. Has the mother the right to destroy the life of the child she is carrying in her womb? Is the right something akin to the possession of some material good, which can be disposed of as the mother wants, without consideration of the right of the unborn child?

Sex pre-selection, sex determination and female foeticide

There are a number of methods available for sex determination and sex selection. Like traditional practices and mores, they are pro-male and anti-female.

Some doctors in India have been carrying out procedures for sex determination. It is perhaps peculiar to India that pre-natal determination of sex is employed for abortion of a female foetus.

Such abortion clinics thrive in the country in spite of public opinion against it.

Whilst many condemn abortion of a foetus merely because it is of the female sex, there are quite a few who justify female foeticide in the Indian setting with its social custom of dowry. And there are quite a few physicians who would like to take advantage of this to make quick financial gains.

The government, though proclaiming against female foeticide, does not seem to be keen to effectively enforce that policy. India has a sex ratio adverse to women (929 women to 1,000 men, according to the 1991 census). The availability of sex pre-selection, sex determination and female foeticide worsens the situation.

There is a growing tendency in many parts of the world to do away with life if the foetus is found to have deformities compatible with life but likely to put a great burden on the family (eg myelocele and paraplegia). The diagnosis of such a condition can be made whilst the child is still in its mother's womb. This tendency is less evident in India. Parents accept such offspring as part of their fate or *karma*. There is a growing number of persons who advocate that the choice regarding whether such foetuses should be aborted be left to the parents.

Infanticide

There are also instances where infanticide of the female child is resorted to. The practice of doing away with the newborn female child if the mother died during childbirth was condemned by Guru Amar Dass, the third guru of the Sikhs, and fell into disuse because of his efforts.

In vedic times there was no reference to infanticide of children born in wedlock but there is a reference to the exposure to the elements of the child born to unmarried women.

Manu, the lawgiver, recommended that the king award the death sentence to him who kills a woman, a child or a *brahman*. "Neither in this world nor in the next can any action leading to the injury of living beings be productive of good results. The conduct of persons who do not perform *vratas* (religious ceremonies) but whose minds are not given to killing can lead to heaven." (7)

The great majority of physicians in India are totally against infanticide, even when the newborn has many defects at birth.

Euthanasia

"Hasn't a person the right to quit a life which, according to him or her, is not worth living? Is the right to die not implicit in the right to live?" (8)

India does not allow suicide or aiding and abetting suicide. This is being questioned. The Law Commission in its 42nd report stated: "It is a monstrous procedure to inflict further suffering on an individual who has already found life so miserable, his chances of happiness so slender, that he has been willing to face pain and death to cease living."

The controversy regarding punishment for attempted suicide has exacerbated with the recent judgements of the High Court and Supreme Court. While the High Court decision was to cut down the provision of punishment, the Supreme Court has overruled it. The present position is that attempted suicide (and aiding suicide) is punishable.

None of our ancient documents allow euthanasia but among our ancient physicians there were advocates for abandoning treatment when the disease reached a stage from which recovery was considered unlikely.

Most people reject positive euthanasia – actively bringing about death. The exceptions are among a few intellectuals. People, by and large, accept suffering as part of their fate, resulting from *karma*. Many favour the omission of treatment with the intention of not prolonging the process of dying. They also favour measures to relieve agony, even if these hasten death.

Artificial insemination/ assisted pregnancy/ surrogate motherhood

The universal desire to have children is strong. What is to be done when there are impediments to having a child in the natural way and there is no way of overcoming sterility in one or the other partner? One way out is adoption. But many desire children with their own genes.

What do the ancients say? According to *Charaka samhita*, "The man without progeny is like a tree that yields no shade, which has no branches, which bears no fruit and is devoid of any pleasing odour." India's social structure requires a son. He is expected to provide support to his parents in old age. He is also required to perform religious rites on their death. A married woman is under social pressure to conceive soon after marriage. A sterile woman is considered inauspicious.

Artificial insemination by the husband or an anonymous donor is practised fairly widely, especially among the upper and middle classes. In vitro fertilisation and other forms of assisted pregnancy are gradually gaining ground. In each case, the cost is high as is the rate of failure. The practice of surrogate motherhood is, as yet, rare in India.

Medical education

The process of training often determines the ethical values held by the physician and the profession. The emphasis given to the teaching of medical ethics can affect the professional behaviour of the future physician. In general, today, there is little emphasis on training in ethics and related subjects. There are a few exceptions but they do not constitute even 10 per cent of the institutions in the country.

Dealing with instructions to medical students, Charaka (9) says:

"Your action must be free from ego, vanity, worry, agitation of mind or envy; your actions must be carefully planned, with concern for the patient and in keeping with the instructor's advice.

"Your unceasing efforts must, at all costs (*sarvatmana)* be directed towards giving health to the suffering patients (*aturanam arogya).*

"You must never harbour feelings of ill-will towards your patient, whatever the provocation, even if it entails risk to your life.

"Never should you entertain thoughts (*manasapi*) of sexual misconduct or thoughts of appropriating property that does not belong to you.

"Take no liquor, commit no sin, nor keep company with the wicked.

"Your speech must be soft, pleasant, virtuous; truthful, useful and moderate.

"What you do must be appropriate to the place where you practise and the time, and you must be mindful in whatever you do.

"Your efforts must be unremitting.

"Do not reveal to others what goes on in the patient's household.

"Even when you are learned and proficient, do not show off.

"Difficult it is to master the entirety of medical science; therefore, one must be diligent in maintaining constant contact with this branch of learning."

According to the ancients, medical wisdom is acquired by three methods:

- study (*adhyayana*), earnest and continuous;
- teaching (*adhyapani*), after examining the student and ascertaining his character, ability, health and interest and imparting lessons concerning life in general, the medical profession, medical ethics and the science of medicine; and
- academic discussions (*tatvidya-sambasha*) with colleagues and fellow students in order to enrich one's own knowledge, to obtain clarity of knowledge, to get rid of doubts, to deepen one's understanding, to learn new methods and ideas and to become skilled in expressing one's thoughts. Active learning is placed before teaching. Medical ethics is among the broad subdivisions to be taught. At the time of commencement, the student had to take an oath. What was more interesting was that the teacher also had to take an oath: "When you on your part keep your vows and if I do not respond fully and impart all my knowledge, I shall become a sinner and my knowledge shall go fruitless." (10)

One major problem in the country today is the development of capitation fee medical colleges, where the admission of students is based upon the payment of a large sum (mostly in the form of unaccounted money) by the student or parent. Today the fee varies from Rs 20 lakh to Rs 30 lakh. Other students, even though they may be far more meritorious – academically and otherwise – are not admitted because they cannot afford to pay the large amount. Because the basis of admission is the capacity to pay the large amount to the management, many unhealthy practices arise. The whole environment has become commercialised and vitiated.

Teaching and patient care are also tainted by commercial considerations in these institutions.

Will medical ethics survive under such conditions?

Organ transplants

There is a big demand for organ transplants, especially of kidneys. These demands and the means of meeting them often raise ethical nightmares because of unscrupulous activities.

There are a small number of transplants where close relatives donate their kidney. This is possible because of strong family ties. The large majority of transplants are carried out on a commercial basis.

Some doctors in India saw a potential gold mine in kidney transplants. There were a large number of patients with end-stage renal disease in the rich Middle East, in addition to rich Indian patients. They were prepared to pay. Kidney transplant became a commercial proposition. A new class of agents or organ procurers came into being. The doctors involved were not bothered about the ethics of robbing a kidney from an unsuspecting person.

It is often the illiterate people of the slums of Bombay, Madras and other places who 'donate' the kidney. At times, even knowledgeable persons are prepared to give away one kidney because they are in desperate need for money. Almost all our kidney transplants have been from live 'donors'. There have been very few cadaveric transplants.

The new Act passed by parliament is expected to favour cadaveric transplantation. It has defined brain death.

Whether live or cadaveric, organ transplantation raises many ethical issues.

Terminally ill

Physicians have been brought up to preserve life and to prevent death. The ancient teaching has been that knowledge that a disease is incurable should not make the physician withdraw care or treatment. As long as the patient breathes, it is the duty of the physician to provide treatment (*tatvat pratikriya karya yavae chvasiti manavah*) (3). But there is also another view: one should know when to stop treatment. Among the qualities that brought

credit to the physician is the withdrawal of treatment of one whose condition is definitely moribund (*upekshanam prakristheshu*). (8)

The two apparently contradictory statements may probably mean that heroic specific treatment was to be withdrawn once the patient was deemed to be terminally ill and that care was to be given to such patients to reduce suffering. The present thinking is in harmony with this view. Prolonging life with the help of machines when there is no chance of recovery or in patients suffering with great pain and distress because of incurable illness has been questioned in recent times (5). If restoration of health is no longer possible and death is imminent, the physician need not do anything extraordinary or heroic to prolong living (dying) but it is proper and necessary to relieve pain and suffering. These measures have to be taken, even if they may incidentally shorten life. The physician is expected to assist the patient in achieving a peaceful death.

To tell or not to tell

According to Charaka and Susruta, the physician must be careful in disclosing to the patient the incurable nature of his illness. It should not be told bluntly (2). It may shock the patient. It is preferably made known to the patient's relatives. State officials are also informed to avoid punishment should the patient die under the doctor's care. Treatment of a heroic nature is to be undertaken only with the consent of the patient's relatives and elders

Present-day doctors differ in their approach about when to tell the truth, and how much to disclose to the dying patient. There are many conflicting considerations: the patient's right to know; the benefit to the patient and possible harm. A study conducted in the Postgraduate Institute of Medical Education and Research, Chandigarh, showed that 69.2 per cent of doctors favoured telling the truth, while 30.8 per cent did not believe in telling the truth to terminally ill patients (11). Most of the doctors favoured involvement of family members and close relatives.

Conclusion

We have moved a long way from the precepts and practices of the ancients. This is true of ethics in general. The medical profession is also affected by the changes. Part of the change has been because

of an erosion of the values cherished in olden times. Part is due to different thinking, influenced to some extent by contact with other cultures. Yet another part has resulted from advances in science and technology. We have been creating situations to which our ethical responses have been slow or even undeveloped.

What is the way out? A judicious blend of the ancient with the modern, integrated with each other to make our responses progressively relevant to the times and needs and based on the cherished ideals of human relationships may be the answer.

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Personal integrity

One of the dominant themes discussed in medical ethics in India is that of personal integrity. It may also have the widest application. Indeed, this is the foundation of ethical guidelines ranging from the oaths of Hippocrates and Charaka to more current guidelines and codes. Medical education must inculcate values in students so that they understand that ethics is a part of their professional identity. However, ethical issues are barely touched upon in the course of medical education in India. IJME *has tried to fill the gap created by the absence of India-specific educational material on ethics. This section contains pieces written by experienced practitioners and medical teachers, giving practical advice and laying down norms for good practice to the benefit of the medical student, medical practitioner and, eventually, the patient. They also look at variations of the physician-patient interaction and the various associated relationships, such as with the consultant, the referring physician, and the pharmaceutical industry.*


WHAT DID YOU OPERATE THE PATIENT FOR?
Rs. 15,000.
NO, I MEAN, WHAT DID HE HAVE?
Oh, Rs. 15,000!
Manpasia

Ethical problems in medical education

F E Udwadia

In this article a senior physician and medical teacher declares that medical education in India fails to equip the student with the necessary attributes and the breadth of vision "that transcends the mere acquisition of knowledge". The problems start with the medical school entrance examination where high marks are no indication of intellectual ability. The system uses outmoded teaching methods that rarely teach ethical principles at the bedside. The writer is aghast at the culture of private coaching classes. There is something very wrong about paying fees for private tuitions. The practice invariably leads to other ethical lapses.

Ethics and morals

Medical ethics is merely one branch of general ethics, therefore it would be wrong to divorce ethics in medicine from the ethics of everyday life. Professor Dunstan gives a succinct but good definition of medical ethics – "obligations of a moral nature which govern the practice of medicine." (1, 2) It is important to dwell briefly on this definition to understand the implications of 'obligations of a moral nature' and 'the practice of medicine'. 'Moral' and 'ethical' are for practical purposes interchangeable words. The term 'moral' raises the practical issues of good and evil, of right and wrong, and of one's obligations as a physician to choose the good or the right course. This is not always easy because one moral obligation may conflict with another different but equally righteous moral obligation in a given situation.

Morals have a basis either in religion, philosophy or socio-cultural traditions. Different concepts in religion, philosophy or in socio-cultural traditions will lead to differing moral principles. It can become increasingly difficult to establish an agreed ethical code in a number of situations where there is a wide variation in the moral

base (3). Even so, the absolute values of good and evil, right and wrong, and the belief in the sanctity of human life, are remarkably similar in all societies.

Medicine – a search for truth

Thus, the three basic, accepted, moral obligations in a doctor-patient relationship in all societies are, beneficence (and its companion-in-arms, non-maleficence), patient autonomy and justice. It is the judicious balance between these obligations that determines ethical decisions in a given clinical situation.

The practice of medicine, in a very broad philosophical sense, is a search for truth, and ethical and moral principles are in-built and inseparable within this search. In a more pragmatic sense, the practice of medicine is both an art and a science. The aspect of science in medicine is more easily understood. For example, it may constitute accurate, measurable observations that lead to a hypothesis, the truth of which is subsequently validated by relevant observations. The art in medicine is an immeasurable, indefinable quantum. It indeed approaches the realm of philosophy, which according to Bertrand Russell is the art of rational conjecture. It is no surprise that physicians have been some of the best philosophers through the ages, and have translated abstract theories of classic philosophy into practical philosophic or ethical action at the bedside.

Medical education and practice

The practice of medicine requires education, knowledge, and wisdom born of experience. It has to be taught and its path illuminated, so that the student who aspires to this practice is shown the way. It is the moral obligation and ethical responsibility of a civilisation or a society to ensure that this is done. The need to equip a physician with the right attributes and to inculcate a breadth of vision that transcends the mere acquisition of knowledge is even more imperative in a fast-changing, increasingly technology-oriented world. If this is neglected, the physician of today and tomorrow may do more harm than good and may well be a hazard to those he ministers to. It is unfortunate that this basic objective in medical education seems to be increasingly ignored in our country.

Medical education all over the world involves selection for admission into medical schools, undergraduate study, postgraduate study and qualification, specialist training and research. I shall briefly consider the problems that plague each aspect of medical education in our country.

Admission to medical school

Entry into medical schools necessitates a selection from a large number of applicants. Universally this is attempted through results of a premedical examination in basic sciences relevant to medicine, and a personal interview of aspiring candidates. It is the height of absurdity that the average level of marks required for admission to medical school at the premedical entrance exam in Mumbai is over 95 per cent. One would have expected brilliance of an extraordinary character (amounting to genius) from these students.

Far from it, the standard at most is average and often pathetic. The fault obviously lies with the premedical education and the premedical exam. Surely a system of examination can be devised where the exceptional few would get more than 70 per cent, the very bright around 60 per cent and the average pass marks are around 50 per cent. A system of examination (as it exists today) where the difference of half or one mark decides admission into medical school, and where so many entrants to medical schools in Mumbai, mediocre though they may be, score near about 100 per cent, is not only absurd but morally and ethically unjustifiable. It needs drastic change and with a little effort this is possible. The system of examination again should not only be different, but should be patently fair. It should be so organised and conducted that allegations or leakage of papers and unfair marking practices are laid to rest once and for all.

Undergraduate medical education costs

Medical education as I see it today is confused in method, content and purpose. The old disciplines in medicine continue to expand taking up time and attention, only to be challenged by claims of newer disciplines, which have opened fresh vistas of knowledge. Good teaching involves a balance between what is old and trusted and what is new and changing. Medicine knows no frontiers. Even

so, the main thrust of undergraduate medical education in our medical schools should be oriented to the health problems and the people of our country. Yet the current trend is to lay greater stress on problems afflicting the West, and a passing or poor reference to diseases that ravage our communities. It is of ethical importance to teach medical students various aspects of community medicine, as only then are they aware of practical health problems that beset the people of this impoverished country. This of course does not mean that we should turn a blind eye to what goes on in medicine in the rest of the world. It only means that we structure our priorities in teaching and in health care correctly.

The method of teaching in our colleges leaves much to be desired. It is dull, dry, didactic and tabulated. It takes no cognisance of current views, current methods and techniques, and often does not utilise the more recent methods of imparting education as for example the use of slides, video recordings, student seminars, project work, clinico-pathological conferences, the use and study of key references that illuminate a subject or that excite interest and curiosity. Good teaching though concentrating on essentials must question dogma, must arouse and encourage an attitude of inquiry and a thirst for knowledge, and serve as stimulus for further study. Above all, a good teacher should use the patient as the chief source of education. The patient is the centre or the fulcrum on which medical education rests. It is wrong for a teacher to ignore this basic tenet. Ward rounds should be rounds where the patient speaks and instructs directly or indirectly, and the medical teacher with consummate art serves as the medium through which the patient instructs.

All teaching whenever possible should be imbued with an ethical slant. Ethics in medicine need not be taught in didactic lectures, but should be illustrated at every opportunity at the patient's bedside. Ethical principles are imbibed by example and precept, so that a good teacher besides teaching well will have a tremendous moral influence on his students.

It is thus both the form and content of teaching that needs to be revamped in all our medical schools. It is the moral and ethical obligation of the medical school that teachers discharge this responsibility to the best of their ability. The sadness of medical

education, to my mind, is the paucity of good teachers and good teaching in our colleges. This is ethically indefensible and is the fount of numerous unhealthy trends that beset the medical profession.

Costs

Medical teaching should always be the prerogative of medical schools and teaching hospitals. It is morally wrong to allow or to encourage medical teaching at a fantastic cost and price through tuitions or coaching classes outside teaching hospitals. What is even more ethically insufferable is the allegation that some of these expensive coaching classes are run by teachers currently employed in medical schools. It is one of the tenets of the Hippocratic Oath that the teacher will teach his students what he knows as a duty and not for a fee.

The practice of coaching classes that claim to assure a successful exam result, and also perhaps ensure marks high enough to get good teaching resident posts, is not only unethical in principle, it is also fraught with numerous other unethical possibilities. There is always a probability, or at least a possibility, of a nexus between the coaching grades, distinctions and prizes at the university examinations. The tentacles of corruption and nepotism can further undermine a system that already leaves much to be desired. The standard of doctors would further fall, medicine as practised by these doctors would inevitably be even more oriented towards mere profit, and the profession would degenerate into a mercenary business where patient care may become secondary or even non-existent.

But then we must pause and ask ourselves: could these unethical eyesores (termed coaching classes) ever have come into existence in our city if teaching in our medical school was interesting, stimulating, instructive and comprehensive? Indifferent teachers and poor teaching in medical schools are ethically wrong and are undoubtedly factors responsible for the spawning of private coaching classes. This again illustrates a principle in medical ethics: one wrong often begets another and another so that we end up with a chain of wrongs.

Private medical colleges

Over the last two decades there has been a mushrooming of private medical colleges in our country, charging capitation fees of several lakhs of rupees. Should such colleges be permitted and even encouraged, or are these colleges unethical eyesores that make a mockery of medicine?

Private medical schools funded by trusts, foundations or even by individuals are not uncommon in other countries particularly in the United States. On principle there is nothing unethical in privately funded medical education, provided the following criteria are met:

- The *raison d'etre* is altruistic and divorced from all profit motives.
- The college has the necessary infrastructure for good teaching, and has a hospital with sufficient number of beds to permit clinical study in all important disciplines of medicine.
- The college is well equipped and has qualified teachers in basic sciences and in clinical subjects with an acceptable student-teacher ratio.
- The funding and all sources of finance are transparently honest, and the fees charged are solely directed towards maintaining and improving medical education and facilities.
- There is accountability in the medical school's administration, and in all its other functions.
- The standard is on par with all other schools in the country.

There are very few schools that meet these standards. If, as is alleged, business ventures come in the guise of private medical schools, the standard of medicine would be deplorably poor and the practice of medicine an unmitigated disaster.

Examinations

There is even today a great deal of mistrust over the fairness of both undergraduate and postgraduate examinations. We read of favouritism, nepotism and even corruption. The degree of canker afflicting the honesty and propriety of examination results is impossible for an outsider to determine, but again it is the moral obligation of the universities to ensure that exams are fair and

impartial, on par with those conducted in teaching centres all over the world.

Postgraduate education

If undergraduate education is in the doldrums, postgraduate education is bound to suffer. Unfortunately, the majority of graduates, if they could, would elect to do their postgraduate studies and specialise. Freedom of choice needs to be tempered by ability, aptitude and resources. Ethically speaking it is preferable to have fewer but well-trained postgraduates and specialists rather than have a veritable army of postgraduates and specialists whose training by international standards leaves much to be desired. It is our ethical responsibility to ensure this is so. An inadequately trained specialist is an even greater danger to health than the poorly taught and trained general practitioner or community doctor. Such a specialist often practises in an uncritical workshop of technocracy, pays homage to and feeds the machine which benefits him, looks at his patients in a specialist frenzy but with blinkers, and loses the all important holistic approach to medicine.

It is ethically imperative that all invasive procedures, diagnostic or therapeutic, in specialist medicine should be taught and then supervised by peers in their respective fields. It is imperative, as in most countries in the world, that to independently qualify to do a potentially dangerous invasive procedure, a specialist needs to do and thereby practise a minimum acceptable number over a period of a year, and then continue to do so. This is sadly lacking in some specialties today and unquestionably contributes to iatrogenic morbidity and mortality.

Research

The last, yet important, aspect of medical education is research. There are undoubtedly some who are born to research rather than patient care. Research again should be on subjects of topical interest. There is indeed great scope for clinical research in our country because of the wealth of clinical material we possess. There is also an equally tremendous scope for epidemiological research – an aspect of disease that is shrouded in ignorance. Is it morally justified to allocate sparse funds for research on some aspect of disease

which has already been researched upon a hundred times over? This has more often than not become the rule rather than the exception in our country. It is important for the concerned authorities to realise that one good research publication is superior to a hundred research papers that repeat what has been said many times over. Integrity in research has deteriorated the world over; the motto "Publish or perish" is the sword of Damocles hanging over the researcher's head. He compromises on scientific standards, on truth, on honesty, and often also on his ethical approach to methods employed to further his research.

In summary, ethics should relate not only to the practice of medicine but to all facets of medical education. Only then will the practice of medicine flower and flourish as it should. That "there is something rotten in the kingdom of Denmark" is obvious in relation both to the practice of medicine and to medical education. I shall not dissect the cause of this canker except to state that it is due to a sharp, progressive fall of values all over the world, more so in our country. When one loses one's sense of values, when the value system is corrupt, the edifice this system supports and embellishes crumbles and disintegrates. One cannot expect the profession of medicine in all its varied aspects to remain a bastion of virtue and probity when it is surrounded by a sea of filth and corruption. The bastion slowly and surely is bound to be eroded and may well be submerged beneath this sea.

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Aha! Mr Sheth, We finally see something that needs removal!
Morparia

Medical ethics: relationships between doctors

R F Chinoy

A lot has been written on appropriate ethical behaviour in the doctor-patient relationship. But doctors are never taught how to interact with their colleagues. The writer here describes the many ways this has not been accomplished as well as ways in which ethical interaction between doctors can be encouraged. She also describes ethical norms governing various other relationships such as between doctors in different specialties and between general physician and consultant. Norms for inter-professional relationships affect not only relationships between professionals but also the treatment of patients. The profession is both a fraternity of equals and a hierarchical group based on self-interest. The writer uses the guidelines of the Medical Council of India to elaborate on the different tensions in inter-professional relationships.

A code of conduct for inter-professional behaviour is, in all professions, an important element of organising the profession. Such a code faces challenges from within, from professionals unwilling to follow norms of conduct. It also faces challenges from without, as professionals face pressure from patients, unqualified practitioners and the demands of the market.

Introduction

Over the four-and-a-half-year span of medical training, students are extensively grilled on how to diagnose diseases and treat patients. The rules of conduct, which should guide his behaviour when interacting with his own professional colleagues, are hardly ever touched upon in the medical curriculum. These rules and laws actually offer a framework within which the future doctor can act. Many students and practitioners are genuinely surprised to know

that rules actually exist. Some know that some sort of ethical conduct is expected of them, but are not very clear on the subject. This essay is an attempt at starting a discussion on the ethics of relationships between doctors.

Forms of professional relationship

The doctor has to play many roles in his professional life. He is both student and teacher during different periods of his career, a patient himself when ill, or a doctor to another professional colleague. More pertinently, throughout his career, he has to regularly interact with colleagues in his speciality and those in different branches of medicine. The forms of professional relationship between two doctors may thus be summarised as follows:

- between student and teacher;
- between doctors (including specialists) in the same discipline;
- between general practitioner (GP) and consultant;
- between two doctors in differing specialities and
- between the doctor and his doctor-patient.

Principles governing the relationship between doctors

It is necessary to clear a general misconception that medicine and ethics are two independent and divergent subjects, or that ethics is merely an adjunct to medical activity. The two are irrevocably harnessed together, and this marriage has been recognised since before the days of Charaka, Susruta and Hippocrates. After all, medical ethics are those obligations of a moral nature which govern the practice of medicine (1). In turn, the practice of medicine, in any field, in any discipline, has been succinctly described as "a long, continuous sequence of ethical moments." (2)

The set of moral principles that must guide members of the medical profession in their dealings with each other is termed medical etiquette. The basis of a good relationship between doctors lies in mutual respect and understanding. A feeling of loyal camaraderie is essential, not only for the sake of the profession but also for the welfare of patients.

Rules or codes of medical ethics are good templates to work on. In this essay, only those comments and rules that apply specifically

to the relationship between doctors will be covered. On this matter, the Medical Council of India declared the following clauses in its code of medical ethics:

- I will give to my teachers the respect and gratitude which is their due.
- I will maintain by all means in my power, the honour and noble traditions of the medical profession.
- My colleagues will be my brothers. (3)

In the same vein, the International Code of Ethics states the following:

- A doctor ought to behave towards his colleagues as he would have them behave towards him.
- A doctor must not entice patients away from his colleagues. (3)

Some rules are clear and precise. However, there is scope for debate and controversy in many of the complex situations of our modern competitive lifestyle. Some of these controversial areas will be dealt with individually, with frequent references to the Indian code of medical ethics. Situations as they exist today will be touched upon and attempts to achieve the ideal will be suggested.

Student and teacher

One of the tenets of the Hippocratic Oath states that it is a physician's duty to teach his students all he knows, freely and without thought for remuneration. At an undergraduate level, the physician (and I use this term in the broad sense which encompasses doctors in all disciplines of medicine) is teaching his future colleagues.

The onus of guiding and shaping a young mind should never be taken lightly. As stated by Dr F Udwadia, "Good teaching, though concentrating on essentials, must question dogma, must arouse and encourage an attitude of inquiry and a thirst for knowledge and serve as a stimulus for further study. Above all, teaching must be imbued with an ethical slant." (4) The professionally sound and ethically upright teacher is in the best position to appear as a role model for his impressionable pupils.

The ideal is sometimes very far from reality. Full-time teachers are often dull, uninteresting and are themselves bored with the monotony of their teaching careers. That they are underpaid and

live in relatively modest conditions as compared to those of their colleagues in private practice does nothing to improve their psyche. The cream of the medical profession is often enticed into making their way to foreign shores, or to the more lucrative avenue of private practice. Teaching jobs are often manned by professionals who start working as a stop-gap arrangement and then just carry on, with very few being truly motivated to take on the vocation of being a teacher. Many teachers view their work as just another job. Many of the truly gifted teachers may not be motivated enough to take on the job because of its limited returns. Some of these same full-time teachers resort to coaching classes to boost their income. This is unethical and is a source of corruption with all the undercurrents of nepotism and misconduct. Students at the undergraduate level are striving not just for the 'pass class'. They know, and the teacher knows, that marks matter tremendously for entrance into the postgraduate training programme. One does not require much imagination to understand the implications of coaching classes run by potential examiners or by influential staff members.

The government has got to realise that teachers at all levels (and this definitely includes school teachers), are in the best position to mould young minds. In order to recruit good and gifted teachers, it is necessary to provide them with salaries and amenities that are realistic and at least on par with the earnings of those in practice.

For those already in the teaching profession, it is imperative to see that high standards of teaching are maintained and improved upon with constant seminars and workshops for teachers. Teaching aids, computers, internet facilities and availability of the latest journals and literature on the subject are not just a luxury but a necessity in the fast changing world of medicine.

At the postgraduate level, it is the duty of the teacher to train the young doctor so that he learns to perform according to accepted international standards.

At present, clinics are held often at erratic intervals and the science of medicine is elaborated upon. Ethical issues may be touched upon in passing, but ethical dilemmas are rarely the subject of detailed discussion. More often than not, the teachers themselves scoff at and ridicule the behaviour and practice of their own contemporaries.

To exercise restraint and maintain the dignity of their profession is something which many teachers themselves need to learn. Students are shrewd and discerning and can easily read between the lines when such comments are made. The effect of snide remarks on their minds is usually the exact opposite of what the teacher hoped to achieve.

Conducting coaching classes at the postgraduate level too is unethical and opens up immense possibilities for corruption and exploitation (3).

At an interpersonal level, sharing of knowledge and dissemination of scientific information are very necessary in our profession. For the advancement of his profession and for his own sake, a physician would do well to affiliate himself with medical societies and scientific meetings and contribute his time, energy and means so that these societies may represent and uphold the ideals of the profession. There is no age bar to the process of learning and it does not matter whom one learns from. It should not be surprising that one day the student may indeed be teaching his own professor in the course of conferences, seminars and workshops. The physician who feels he knows it all and has seen it all is dangerous. Sooner or later he is going to harm some of his patients because of his inability to keep up with the times and learn about recent advances and techniques.

Professional services of physicians to each other

A physician should consider it a privilege to render service to his colleagues and their immediate dependants. The Indian code of ethics urges a physician to "cheerfully render professional services to his physician-colleagues and their immediate family members without seeking monetary compensation." However, there is no rule that a physician should not charge another colleague for his services (3). When called from a distance to attend to, or advise, a colleague he should be reimbursed for travelling and other incidental expenses. Unfortunately, many doctors who themselves require specialised or professional help from their colleagues cheat on them by seeking free treatment for themselves, their families and also for friends and distant relatives. This is unfair to the treating colleague, who gives of his best without receiving compensation

for his time and efforts. In this context, the terms 'immediate family' and 'dependants' require definition. The immediate family consists of parents, spouse and children. Dependants include non-earning members of the family dependent upon the doctor for their survival.

Duties of the physician profession at large

Doctors may criticise one another, but only face to face and in complete confidence. To criticise a colleague in front of a patient is both damning and dangerous and can never be justified.

It is equally important that the utmost care and tact be maintained when listening to patients complaining about how they have been treated or handled by other doctors. A patient who dislikes or develops a grouse against a doctor based on some real or imagined mistake can be extremely disparaging and indiscreet in his manner of speech. The mature doctor would do well to refrain from listening to this tirade against a colleague. If, however, he cannot restrain the agitated patient, he must studiously refrain from making any comment that could possibly be construed as acceptance of the patient's criticism. Professional loyalty demands understanding and mutual respect for your colleagues.

On the other hand, a doctor is urged to expose incompetent or corrupt, dishonest or unethical conduct on the part of members of the profession without fear or favour as these are against the best interests of patients. The accused doctor may be an alcoholic or a drug addict or a debauched person. Such matters may have to be considered by medical tribunals or by specially appointed ethics committees if they are not already sub judice. This cannot be considered as licence for witch hunting or slander. The responsibility is grave but must be followed through with courage and honesty.

Ethics of employment obtaining assistance of non-medical men

In the matter of employment of personnel who would be required to render professional skill and discretion, the physician is morally obliged to recruit qualified attendants who are registered and enlisted under the law in force at that time. Those who are deficient in character or education should not be allowed to attend, treat or

perform operations upon patients, as this is dangerous to public health. By enlisting non-medical men for medical tasks, the physician denies his colleagues jobs and, at the same time, does a grave disservice to his patients. If, however, the clinician does employ assistants to help him, the ultimate responsibility in the event of any mishap rests solely with the doctor.

A doctor asked whether he could utilise the services of a clinical laboratory which was not being operated under the supervision of a qualified pathologist but was run by a science graduate who had no medical qualifications. The reply of the Maharashtra Medial Council was as follows: "The medical practitioner should not co-operate with the clinical laboratory conducted by a BSc who neither has medical qualifications nor works under the supervision of a medical man. Such a person, by himself, is not competent to assess the results obtained and as he is not directly under the control of the medical council, a report submitted by him, if incorrect, will reflect upon the medical practitioner who acts on the report." (3)

The burgeoning home industry of small laboratories run by laboratory technicians or by mere science students or less is on the rise. There are, at present no curbs on this sort of activity. The truth is that they prosper and multiply because they are patronised by members of our own profession who find such laboratories cheaper than those run by professionally qualified pathologists and microbiologists. The danger to patients from this selfish measure can be considerable. In addition, injustice is done to our own qualified colleagues.

There is also a proliferation of diagnostic and imaging centres which are run as businesses, manned by smart but ill-qualified personnel. The public may not be in a position to understand the threats this may pose to their health. It is necessary for our profession and the medical councils to take cognisance of these centres and force them to run with some form of a licence under the guidance and direction of a fully qualified doctor. They, too, along with the pathology and microbiology laboratories, must be subject to reviews and surprise checks similar to those for blood banks.

The practice of doctors running drug shops, dispensing drugs and appliances prescribed by other physicians also needs correction. This is the prerogative of the qualified pharmacist. A physician

should not run a shop for the sale of medicine or for dispensing prescriptions prescribed by doctors other than himself, or for sale of medical or surgical appliances. This does not mean he cannot prescribe or supply drugs, remedies or appliances for his own patients, so long as there is no exploitation of the patient.

Advertising

The physician who sets up practice and announces his presence with an unusually large signboard is probably not breaking the law, but he is certainly acting unethically. A doctor's signboard cannot have the status of a glossy hoarding. Both signboard and the doctor's prescription pad should proclaim nothing more than the physician's name, qualifications, titles and speciality. It is improper to affix a signboard on a chemist's shop or in places where he does not reside or work.

Advertising lowers the dignity of the profession and entices or lures patients on the basis of glamour rather than competence.

The Maharashtra Medical Council is aware of the growing menace of doctors who seek self-glorification and who market themselves in newspapers, magazines and on television. Doctors, surgeons and many quacks have been known to make tall claims of successful and fantastic surgeries, guaranteed cures for obesity, cancer, AIDS and other diseases. Such individuals cannot wait for their work to speak for itself. Instead, they indulge in talk shows, consultancy columns in newspapers and advertisements of their arrivals and departures in various cities.

The Maharashtra Medical Council is now taking cognisance of doctors who advertise for various drugs, toothpaste products or remedies on TV and is also proceeding against doctors who place huge advertisements in newspapers for slimming programmes and other quick money-making programmes. Self promotion in any form is a punishable offence under the rules laid down by the Medical Council of India and the state councils. These also bar doctors from publishing their photographs.

Unless the councils force the medical profession to realise that such conduct will debar doctors from medical practice, this cheap exhibition is likely to worsen.

A physician cannot claim to be a specialist unless he has put in a number of years of study and experience in the speciality, or has the appropriate university qualification. Once he becomes a specialist, he cannot and should not work outside his specialty even for his friends. The ramifications of this statement are far reaching. Cross practice of allopathy and other disciplines of medicine like homeopathy, unani or ayurvedic medicine is wrong and it behoves the clinician to restrict his practice to the discipline he is specifically trained for. Dabbling in other sciences is unethical and potentially dangerous. On a similar note, the anaesthetist, for instance, should not do general practice. Nor should the neurosurgeon dabble in conditions that fall within the domain of the neurologist. There is, however, scope for debate on this issue when considering physicians who practise in rural areas, where they are forced to offer services on many fronts because of the non-availability of qualified or specialist help. The rules have to be viewed in the context of the circumstances and the intentions of the physician.

An institution run by a clinician for a particular purpose, such as a maternity home or sanatorium or home for the blind or aged, may be advertised in the lay press, but such advertisements should not contain anything more than the name of the institution, types of patients admitted, facilities offered and the residential fees. The names of the superintendent or the doctors attending should not appear in the advertisement.

The code of ethics forbids cheap exhibition by doctors in the form of interviews and articles published for the purpose of advertising themselves or soliciting practice.

The doctor is permitted to write to the press under his own name, on matters of public health or hygiene, or to deliver public lectures or give talks on the radio or television on subjects of public interest. He is also permitted to make a formal announcement in the press regarding the following:

- starting practice,
- change of type of practice,
- change of address,
- temporary absence from duty,
- resumption of practice and
- succeeding to another practice.

On a more pragmatic note, the Indian code of ethics categorically states that the "solicitation of patients directly or indirectly by a physician, by groups of physicians or by institutions or organisations is unethical." The physician who advertises his skills, achievements, and qualifications lowers his own dignity and that of the profession.

No physician should use touts or agents for procuring patients. He should neither pay nor receive a commission for referring patients.

Etiquette of inter-professional relationships

The British Medical Association (2) and the Medical Council of India (3) state that a practitioner in whatsoever form of practice should take positive steps to satisfy himself that a patient who applies for treatment or advice is not already under the active care of another practitioner before he accepts him. Furthermore, a practitioner should not accept as a patient any patient whom he has attended as a consulting practitioner, or as a deputy for a colleague. Implementing this directive is not an easy task in a country like ours where private practice is rampant and where patients often switch doctors at will. Patients literally go shopping from clinic to clinic, or from hospital to hospital for doctors' opinions. Unscrupulous doctors readily accept any and every patient, often with full knowledge that the patient is under the care of a colleague. Such a commercial approach to patient care reduces the profession to a business venture.

Ethics in consultations

Consultations are a time-honoured custom and they should be encouraged in cases of serious illnesses, especially in doubtful or difficult conditions. In every consultation the benefit to the patient is of the first importance. The rights of the patient to ask for a second opinion should be respected. As in most situations, the attending practitioner is the best judge but his vanity should not prevent him from recommending it, or from acceding to the patient's request for consultation with some other doctor. No medical practitioner can claim to be a specialist in every branch of medicine.

The following suggestions made by the Maharashtra Medical Council in its Code of Medical Ethics tersely state the important

circumstances under which a practitioner should ask for a consultation:

- in serious illness,
- in doubtful conditions,
- in operations of a mutilating or destructive nature upon an unborn child and
- in operations which may vitally affect the intellectual or generative function of the patient. (3)

The attending doctor may certainly suggest the names of the consultants of his choice but even then, in the event of a difference of opinion between him and the patient or the relatives of the patient the choice of the latter should prevail.

In the event of an irreconcilable difference of opinion between the two doctors, the circumstances should be impartially and frankly explained to the patient concerned. It is now up to the patient to decide which of these he will follow or, indeed, whether he will seek further advice from a new consultant.

There are points on the proper etiquette of consultation laid down in the International Code of Ethics which are summarised as follows:

- The attendance of the practitioner should cease when the consultation is concluded unless the patient has dispensed with the services of his first doctor and engaged those of another.
- In no case should the consultant treat the patient alone or hand him over to his assistant or admit him to a nursing home or hospital without the knowledge of the referring physician or injure the latter's position in any respect. (Emergencies form an exception to this rule. In such an event, the consultant should inform the referring physician at the first opportunity after the crisis has been tided over.)
- When a consultant sees a patient in his rooms at the request of a medical practitioner, it is his duty to write to the latter, stating his opinion on the case and the line of treatment he thinks should be adopted. He should not see this patient again without a fresh note from the first doctor.
- A doctor called upon in an emergency must treat the patient, but after the crisis the consultant must retire in favour of the original attendant of the patient.

Fees – insofar as they concern our colleagues

A practitioner's fee should be commensurate with the services rendered and the patient's ability to pay. They must be reasonable. It is advised that his fee be on par with those charged by his colleagues. The Medical Council of India's code of medical ethics further states that remuneration received for medical services should be in the form and amount specifically announced to the patient at the time the service is rendered. It is unethical to enter into a contract of 'no cure no payment'.

The practice of splitting fees must be condemned as infamous conduct. A medical man is a professional. He is not doing business. Splitting of fees stinks of commercialism.

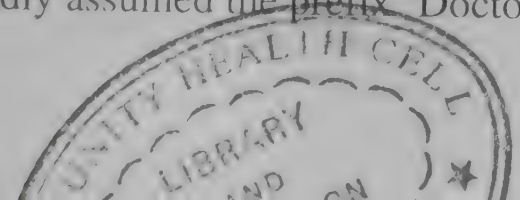
Dichotomy or splitting of fees is illegal. When a practitioner consults a specialist in the interests of his patient, he is not acting as a business agent. The practitioner has no right to demand or expect a cut from the specialist for calling him in. The specialist in turn can charge the patient the appropriate fee for his consultation visit.

Conclusion

The Code of Medical Ethics offers this advice: "To other members of the profession you owe a duty as a colleague. You should never do or say anything that may make the position of your colleague awkward." There is a vast body of literature on ethical issues written by medical men, lay public and by those who understand the law. One sardonic statement, obviously written by someone who had clashed with the medical profession, reads as follows: "There are three subjects on which the medical profession in general is woefully weak. They are manners, morals and medicine."

Ironically the author of that comment was himself a doctor. There are many people in different walks of life who share this view.

On introspection, there is no doubt that from time to time doctors do forget their moral obligations to each other. Our colleagues and the layman are quick to notice these deviations. If we aspire to retrieve the situation, we need to look back at our graduation day and have another close and honest look at the oath we swore when we so proudly assumed the prefix 'Doctor'.



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The ethics of medical referral

Eustace J De Souza

At the heart of medical practice is the physician-patient relationship which is based on trust. This relationship is an unwritten contract where the patient consents to advice and treatment given by the doctor while the doctor assumes responsibility for the patient's welfare. The writer discusses matters that arise when the doctor or patient consult another physician, introducing a third party — whose obligations are less well defined — into this contract. The third party's entrance may not always be in the patient's interests, or with the knowledge of the doctor. There may be other, pecuniary, interests, such as kick-backs for the referring doctor. At times, a patient shops around for specialists without the knowledge of his primary doctor.

Introduction

The relationship between doctors and patients has undergone a sea change in the last 60 years. The old family physician is fast disappearing, no longer friend, philosopher and guide.

Advancing technologies and umbrellas of chemotherapy and antibiotics now override careful history taking and clinical examination.

Finally, the taint of lucre can tip the scales of ethical restraint.

Various arguments are raised. "Is not the labourer worthy of his hire?"; "Doctors too, must live"; "The cost of medical education is so high, and even a room to practice in costs a bomb"; "In all justice, is he not entitled to a fair return?"

These may be fair questions but can never justify unethical conduct. This is the first criterion that must pervade the medical profession if it is to rise above the ethic of the market place.

A patient made aware by the media of these concerns weighing on the medical profession may question the essence of the fiduciary contract between doctor and patient.

When we add to this the ambit of the Consumer Protection Act (CPA), we are certainly at a crucial crossroad. If the CPA is empowered to view the professional services rendered by a doctor as goods, on the same plane as a toaster supplied by a manufacturer, we lose sight of several subjective factors that separate a professional service from goods supplied.

In the latter case, objective criteria of claims made or protections prescribed can clearly be spelled out and independently tested. Obviously, to protect themselves doctors prescribe or at least recommend that certain objective tests be undertaken. While perfectly certain of his diagnosis, the doctor feels he must order the test primarily as 'insurance protection'. Naturally, this raises the cost to the patient.

The doctor-patient contract

When a patient comes to a doctor, whether he knows it or not, a contract comes into effect. This contract is essentially between two parties who agree to deliver on the one hand and to receive on the other.

Between doctor and patient, this contract is essentially based on faith. His consent can be inferred by his voluntarily coming to the doctor for assistance, or in some cases made overt when he signs a declaration accepting some mode of therapy, especially in declarations for admission to hospitals or nursing homes. In public hospitals (and to a slightly different degree, in private hospitals), the hospital is the 'delivering' party and its doctors are, in a sense, its special agents. The honorary doctors are not paid agents and bear a greater degree of independent responsibility.

Introducing a third party

I have particularly indicated two parties with regard to this contract, because the question of a referral immediately involves a third party or person into this contract.

The problem of the third person must be seen in the light of individual rights and obligations as well as professional responsibilities and inferred ethical norms, codes and guidelines.

A fundamental principle in medical ethics holds that the human being has a unique value, status and dignity. In no professional transaction must the obligation to uphold this right be violated.

While the first consent can be inferred, in a referral this consent cannot be so easily inferred. The patient must be informed of the new entrant into the contract, with reasons for the introduction of this third party. In this circumstance the third 'person' or specialist is called because the conditions of the case warrant the need for another supportive or additionally required form of expertise. Thus it is the welfare of the patient that is the only reason for this referral.

Here lies the evil of the kickback or 'commission'. In trade or business, a commission can be part and parcel of the mechanism of the contract, where the prime purpose of commerce is profit. The ethics of business is primarily the prevention of fraud or exploitation and the gimmick of false representation by skilfully worded advertising, where glamour is often a cover. The ethical 'evil' here lies when the skill is often deliberately used to carefully skirt the law of misrepresentation or actual fraud.

In business, another ethical difference is that of 'putting one over' a serious competitor by skilful advertising which is forbidden in professional ethics.

The question of responsibility

In the matter of medical referral, there is also another ethical consideration with medico-legal significance.

It is the question of primary responsibility. This depends on the nature of the referral.

If, for instance, it is a consultation between general practitioner and specialist, the latter is mainly responsible for the continued care and concern for his patient. The general practitioner merely follows the advice of the consultant, reporting to him the progress of the patient so as to modify therapy or obtain further instructions with regard to continued care.

On the other hand, if the referral is such as to need the independent care by the consultant, the patient is transferred to the care of the consultant. The general practitioner moves aside, though courtesy and etiquette demand that the consultant keeps the referring doctor informed of the progress of the patient. Once the immediate

specialised care is completed, the patient can then be returned to the general practitioner for such continued care and advice as may be necessary.

Unfortunately, in both public and private hospital health care systems, the patient decides for himself which consultant specialist or department he should go to. The result is a waste of time, undue expense and the unnecessary shuffling of a patient from one consultant to another. For instance, a young woman decides that her pain is due to appendicitis and goes to a surgeon. He decides that there is no disease in the appendix but suspects the need for gynaecological intervention. The patient is referred to a gynaecologist. A general practitioner would have identified the need for a gynaecologist and made the appropriate referral, at diminished expense and certainly a saving of valuable time on the part of consultants as well as the patient. The two-tier system, which poses definite advantages, needs to be resuscitated. Here all patients can be first seen by individuals or teams of general practitioners adequately qualified to treat and deal with the ordinary run of ill health while at the same time equally qualified to know which consultant to go to and to order appropriate tests prior to the visit to the consultant.

Referral of patients admitted to hospitals

In-patient referrals, both in public and private hospitals, are either for particular supportive consultation or to effect a transfer to another appropriate speciality. Generally, these consultations are facilitated between the various consultants on the staff of the hospital. If a patient seeks another doctor not on the staff, he has a perfect right to seek discharge from the hospital to be treated by the doctor of his choice elsewhere.

Respecting patient autonomy, in some private hospitals there is a provision whereby the hospital will permit the second consultant (not on the staff of the hospital) being called at the request of the patient provided the current treating doctor also agrees. If it is a mere consultation, the original treating doctor bears full responsibility for continued treatment. In cases of surgery where an outside consultant is actually involved in the surgery jointly, it is only ethical that both doctors continue to bear joint responsibility.

Legally, this problem of joint responsibility is quite vexing. However, the doctor in whose unit or under whose care the patient is registered cannot abdicate responsibility, unless the patient has been transferred to the care of another specialist who must accept this independent responsibility. Here, too, the patient's informed consent is an ethical necessity.

Second opinion

In the matter of referral, it sometimes happens that the patient will ask (rather hesitantly – for fear of offence) that the treating doctor agree to a second opinion. No one should see this as a lack of faith but rather respect a patient's right to total autonomy and gladly give his consent unless he honestly feels it would not be in the best interest of his patient. In this latter case, he should explain his reasons for not agreeing, but clearly leave his patient free to seek treatment from the other doctor. However, as the doctor too has rights and professional autonomy, he should make it clear that the discharge from his care also involves discharge from future responsibility. Incidentally, this discharge does not absolve the first treating doctor from proven incompetent or negligent treatment while under his care. Thus, if the second surgeon were to operate again and find that a swab had been left behind, the first operating surgeon is ethically, morally and legally responsible.

It frequently happens that a patient 'shops around' from doctor to doctor, often in the hope of getting an opinion that he or she would find either convenient or conforming to pre-formed expectations. Or the patient seeks treatment from one doctor for a period of time, then leaves to go to another without telling the second either the details or facts of the previous treatment.

Doctors should understand that patients are human beings, especially vulnerable under the burden of sickness. While the doctor is certainly entitled to a true and full past history, failure on the part of the patient to disclose an earlier consultation should not always be construed as an inability to keep the faith so vital to the contract. Prudent questioning is certainly the right of any doctor who is concerned to give of his best to his patient, and part of good history taking.

Can a doctor refuse to treat a patient?

Being a professional in his own right, the doctor certainly has an ethical right to refuse to treat a patient who will, in his view, not follow treatment directions to their logical ends.

This right not to treat or accept for treatment also extends to those situations where a patient approaches a doctor insisting on a predetermined mode or line of treatment.

My only plea in this context is that the doctor is a man of morality first. By morality, I mean that every man, be he theist or atheist, agnostic or secular humanist, has the right and obligation to choose between what he sees as right and wrong. Every doctor is a professional, who by his chosen vocation agrees to abide by a code of ethics guided by morality. Finally, as social beings, both doctor and patient are guided and restricted by the laws of the land in which they live. They may not agree with those laws. For this they must seek legal redress to get these laws changed.

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An objective look at 'cut practice' in the medical profession

P A Kale

This distinctive feature of Indian medical practice is a matter of great concern for ethical doctors and for patients. The author describes the various types of fee-splitting within the modern medical system, and why it leads to malpractices and can harm the patient. Patients may be subjected to unnecessary investigations and receive substandard care. A solution requires fundamental change in every aspect of medicine, from remuneration to public hospital staff, transparency in the fee structures of general practitioners and consultants, continuing medical education and universal insurance to external deterrents such as consumer courts and greater public awareness.

Introduction

All doctors qualified to practise modern medicine take the classical Hippocratic Oath before beginning their professional careers. The idealistic values learned during the period of training get shaken up when the doctor steps out from a world of 'practice of medicine' to one of 'medical practice'. Here he sees 'practical' adjustments that he is required to make in his clinical and therapeutic decisions, and encounters open offers of referral of patients for a predetermined and regularised practice of fee-sharing ('cut practice'). Since the schedule of charges for professional services is totally individualistic, the illegal and unaccounted fees to be given to the referring doctor usually get added on to the specialist's fees and are paid unknowingly by the patient.

How ethical is this practice? The subject is debated by doctors in social and academic get-togethers but a status quo has persisted with some doctors for and some against it.

Variations on the theme

Cut practice occurs in many forms. I list some of them:

- Giving a share of fees to the referring doctor.
- Referring patients for unnecessary consultations or tests to ensure a kickback from the consultant or laboratory.
- Giving expensive gifts periodically to the referring doctor.
- Appointing junior specialists to a super-specialty hospital so that procedural work is always referred by them to you.
- Sponsoring of a conference or payment of travel expenses by a company in return for the use of its equipment or prescription of its drugs.

If one reads the Hippocratic Oath carefully, there is no condemnation of the act of sharing one's fees with another doctor involved in the care of a particular patient. It is only by implication that the Oath stipulates that a doctor shall charge a reasonable fee and will not increase it for sharing it in order to obtain a larger number of referrals.

Basis for charging fees

Every doctor determines his/her professional fees on the basis of experience, wisdom and self-perception of the level of skills required for a particular treatment. Fees thus vary widely from doctor to doctor. Hence a particular amount cannot be termed unreasonable as long as the patient is aware of the sum to be paid before the service is rendered. What the treating doctor does with the fee after he receives it is entirely and solely his concern and the patient or any other person has no say in it. Hence if a doctor decides to give a portion of his fees to another person (medical or non-medical) it is entirely legal and ethical to do so, provided this is done openly and after obtaining a receipt.

However, such disbursements occur only in theory. In actual practice the referral pattern is based more on the fact that a particular doctor is ready to split his fees rather than that he is the best qualified to render a particular treatment. Several malpractices accompany such referrals. The limitations and scope of a particular procedure are not fully explained in advance. Patients are admitted to a hospital or nursing home in spite of the fact that the place is not adequately equipped to impart a standard of medical care available at another place in the area. Patients are referred to manifestly substandard

laboratories. Reports from such laboratories are manipulated to suit the requirements of the referring physician.

Various specialised procedures – such as endoscopy, angiography and angioplasty – form lucrative sources of income and are therefore frequently advised even when the stated indications are not scientifically valid. (At times it is difficult for a doctor to say that the procedure advised by another was not required because on most such issues, opinions published in the medical literature support both points of view. There is truly no substitute for one's own competence and conscience acting as an internal judge and counsel.)

A malpractice that has come to stay

Pernicious as it is, the cut practice has come to stay. The medical profession itself has nurtured it. Indiscriminate proliferation of medical colleges with open and shameless support of those in power is adding hundreds of inadequately trained medical graduates every year to the pool of practising doctors. A large majority of these are concentrated in urban areas with attendant intense competition and battle for survival which favour cut practice. In the absence of a clear, logical, bold and community-oriented health care policy on the part of the government and a lobby of strong, honest, clear thinkers representing the medical profession in the corridors of power, the present situation is unlikely to change in the near future.

Some practical alternatives

All financial transactions between doctor and patient must be above board with receipts being provided to the patient.

- Each general practitioner must charge a publicly stated fee from the patient for the act of medical examination, making a diagnosis and recommending appropriate treatment or referral to an appropriate consultant or hospital.
- A fixed percentage of the specialist's fees for procedures should be openly given to the family doctor on the ground that the latter will offer follow up care to the patient at his home after the procedure. This measure also transfers legal responsibility on to the family doctor for competent medical care.

- A body of experts in each hospital or nursing home should monitor the performance of various procedures to ensure that they are based on scientifically valid indications.
- Health insurance should be made compulsory and fees for various examinations, procedures, visits, etc, should be fixed from time to time by a committee of professionals consisting of representatives from the medical bodies, insurance companies, government and the legal profession.
- Medical councils at central and state levels should be given adequate powers to punish erring doctors even without a formal complaint. At present positions on such councils are used only to enhance one's prestige and members of the councils are almost completely incompetent.
- The annual output of medical graduates should be governed by actuarial data like annual loss of practising doctors, density of doctors in a given area, the local population and its medical needs and so on. If an area has a supersaturated doctor/ population ratio in a given speciality then the redundant doctors should be made to relocate to another suitable area.
- The monthly salary and other benefits of full-time doctors, especially in teaching hospitals, should be such that they are able to maintain a decent standard of living commensurate with their position and seniority. There will then be no need or incentive for unethical ways of earning extra income. The present pay structure is insultingly low in this respect.
- Compulsory attendance by general practitioners and consultants at continuing medical education programmes will help to bring about uniformity of approach in management.

An increased general awareness and education in society and fear of consumer courts will certainly act as an external deterrent as in western countries.

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Morparia
A VICTIM OF CUT-PRACTICE

The physician and the pharmaceutical industry

G D Ravindran

The pharmaceutical industry and the medical practitioner are inter-dependent: physicians need the industry's drugs and the industry must rely on the physician to prescribe them. But the industry spends nearly 15 per cent of its gross income on promotional practices –literature, free samples, gifts, incentives, sponsorships, seminars and the like – to influence the prescribing practices of doctors. The author discusses the various ways in which a physician's duty towards his patient is subverted by such inducements. A particularly topical issue discussed here is the involvement of general practitioners in medical research where they are unaware of the research protocols and have no control over the data.

The drug industry, the medical profession and the patient have a unique relationship. The industry makes products that it cannot sell to the patient (consumer) directly. On the other hand, the medical profession cannot treat the patient without drugs produced by the industry. Thus the industry and medical profession are interdependent and have a common aim. One should be able to evaluate them according to the principles of beneficence, non-maleficence, patient autonomy and justice. The industry must provide drugs to the patient, not manufacture drugs that have harmful effects. It must make reasonable profits and help in the research of newer drugs.

The primary objective of this joint effort is to alleviate pain and suffering. The secondary objective is to be rewarded for this effort. The drug industry expects a profit and the physician expects a suitable reward. There is nothing improper in these objectives.

As in all partnerships there can be conflict between the partners. One major area of conflict is the industry's tendency to influence doctors. The KeFauver Committee hearing on drugs states: "The incidence of disease cannot be manipulated and so increased sales

volume must depend at least in part on the use of drugs unrelated to their utility or need or in other words improperly prescribed. Human traits can be manipulated and exploited and this is a fertile ground for anyone who wishes to increase profits."

Advertisements

Drug promotion and advertisement are a major part of the drug industry's budget. In 1988, the top 16 companies in the United States spent about $85 million in this area, up from $6 million in 1974. Companies are estimated to spend anywhere between six and 15 per cent of their gross income on drug promotion. No business enterprise would spend shareholders' money unless it was sure of getting something in return. If advertising does not influence, a lot of people are wasting a lot of money and time.

The word 'advertise' is derived from the Latin word '*advertere*' which means 'to turn towards'. Advertising is generally regarded as a legitimate means of fostering the competition that drives a free market economic system. The moral justification is that consumers benefit. Businesses that satisfy consumers will prosper at the expense of those that do not. Consumers are presumed to benefit from advertising because it is presumed to broaden their choice and maximise their chances of getting the most value for their money. Yet advertisements by their very nature simplify and contain an element of potential deception. Virtually any advertisement is capable of misleading, though it can be made less misleading by the addition of detailed disclaimers.

Drug advertisements which include product information are circulated to health professionals through journals, medical representatives and the mail. Persuasive advertising highlights the product's beneficiary properties. "X the drug of choice for enteric fever." Certain facts can also be manipulated, focusing on the good effects without mentioning the bad effects. "The typhoid bacterium resistant to many antibiotics except X..." Finally, advertisements can also intimidate to get the doctor to prescribe: "The top 100 doctors prescribe X for enteric fever: Do you belong to this group?"

This process of simplification, highlighting and concealing enables companies to withhold essential information on indications and

contraindications and to sell a drug differently in different parts of the world.

Medical representatives

The main promotional thrust of the pharmaceutical industry is through its medical representatives (reps). There is one rep for every four to five doctors. The meeting between a doctor and the rep leaves little to chance. Reps profoundly affect the way a doctor prescribes. They have been aptly described as the 'stealth bombers' of medicine. Their bottom line is: "Prescribe my drug." These are invariably polite and reasonably knowledgeable. Before meeting a doctor they study the doctor's prescribing habits on the basis of information gathered from local pharmacists and a preview of patients' prescriptions. They also get to know something about the doctor's likes and hobbies, family life and social interests and generally cultivate them. It has been estimated that it takes between one and two years before a practitioner can be prevailed upon to change practice.

Some reps categorise doctors according to whether they are 'conservative' or 'risk takers'. Conservative doctors will not try out a new product unless it has proven itself. Risk takers are willing to try out new products; reps will try and obtain a commitment to use new products on a few patients. Conservatives will start using new products only when used by opinion formers or local consultants, also called 'educationally influential physicians' – hospital consultants in major hospitals whose prescriptions are imitated by other practitioners.

Reps try to persuade doctors into trying their products by using reason. If it fails, then they try to manipulate by offering gifts, or by intimidating them or by appealing to their professional pride. If all fails, then they appeal to the doctor's mercy "If you do not give me business I will not get my salary."

As the major source of information for a majority of doctors and pharmacists, medical reps have a role in helping practitioners know about the drugs available in the market and their costs. It is the practitioner's duty to use reps while taking care not to be unduly influenced by their sales pitch.

Gifts act as regulators of human relationships. By offering a gift a person is really offering a friendship. Accepting a gift is accepting the initiation or reinforcement of a relationship and triggers off an obligatory response. The recipient generally assures grateful conduct and reciprocation of the gift. While giving can be an act of generosity, it also serves the self-interest of the giver.

Gifts may be personal when given to an individual or impersonal when given for a cause. A donation to the AIDS fund of the hospital may be impersonal; a donation to the hospital director is personal.

The physician accepting gifts has three major ethical dilemmas. Gifts cost money and the cost is ultimately passed on to the patients. Secondly, gifts may erode the concept that the medical professional best serves his patient's interest. Thirdly, they establish a relationship between the donor and recipient.

The following ethical issues are involved

They are in conflict with the principle of distributive justice. The drug company spends the patient's money for the doctor's benefit without the patient's knowledge. The burden is passed on to the patient and the benefits are passed on to the physician (gifts) and the drug companies (profit). A medical bag presented to physicians by a company manufacturing anti-TB drugs will be funded from profits that the company makes from the sale of anti-TB drugs. Many patients may have struggled to buy these drugs.

They interfere with the patient-doctor relationship. Physicians are supposed to safeguard the patient's interests. Accepting gifts may interfere. A physician may be influenced by the gift to prescribe a particular brand of drug when more cost-effective brands are available.

They affect the physician's character. Gifts may disturb the delicate balance in every physician between self-interest and patient welfare. Conscientious physicians may be especially vulnerable to the obligation that comes with gifts.

The practice of medicine requires a constant balancing act between altruistic concern for others and one's own self-interest and ambition. Gifts from drug companies feed our human tendencies towards self-interest but do nothing to foster concern for our patients.

The General Medical Council of the UK

It may be improper for individuals to accept, from a pharmaceutical company, monetary gifts, loans or expensive items of equipment for their personal use. No exception can, however, be taken to grants of money or equipment by a firm to an institution, hospital, health care centre or university department when they are donated for the specific purpose of research.

To the best of my knowledge, there are no specific guidelines laid down and expounded by the Medical Council of India. Hence it may be useful to refer to those laid down by the General Medical Council of the UK.

The term hospitality has been used very frequently. Hospitality means friendly and generous entertainment of guests.

Should a physician accept gifts like paper pads or ball pens? Most people would consider this practice acceptable. The grey areas come when it concerns larger gifts. Holidays and sponsorships for attending conferences are unacceptable.

Drug companies are also involved in holding seminars, conducting research and sponsoring programmes of professional societies and institutions. Though this does not affect physicians directly, there is always a fear that office bearers of the society may be influenced. Sometimes the topics for seminars are chosen in such a way that a drug can be promoted. Drug companies may influence the speakers. Sometimes they provide useful continuing medical education for the physicians but most often these symposia tend to promote a particular drug.

Research

In our country the Drug Controller requires a multi-centric trial to be conducted before it accepts a drug, even if the drug has already been established in the West. Many general practitioners nowadays get carried away by the importance placed on research. This research involves getting general practitioners to try the new drug on their patients. But what if a newly-started drug is found to be beneficial to the patient but becomes unaffordable after the trial is over? Hence it is essential that researchers discuss the drug

protocols, the way the results will be handled and the control of data that is generated by the study.

We must be constantly vigilant that we keep the interest of the patient at heart and not be led astray by drug companies.

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Whistle-blowing in the health-related professions

Gerald Vinten

Should you speak up if you witness unethical or illegal practices being condoned by your seniors? Whistle-blowing is a controversial topic. Some regard it as an ethical duty and others believe it is irresponsible professional behaviour. The law usually sides with the authorities. Whistle-blowers have been punished for speaking out. In this context it is interesting to know that most whistle-blowers are not deviant employees, but law-abiding and sincere people.

Introduction

The correspondence and publicity following the disciplining and subsequent settlement in his favour, prior to an industrial tribunal, of Stockport Health Authority Charge Nurse Graham Pink, suggested that the urge to blow the whistle was at almost epidemic proportions in the British National Health Service (NHS). It might be surmised that the only device that kept this under control was the fear of discipline and dismissal. This fear has been increased by the contracts of employment of the NHS Trusts which have outlawed whistle-blowing. There are similar pressures for those working in other health-related professions, and in health and safety and environmental protection (1).

It is important to question whether such severe strictures are in the public interest, or whether they are there to make the life of senior managers easier, or to make it possible to ensure that doctors, nurses and other caring professionals and support staff conform to budgetary constraints without resort to campaigning.

Definition

Despite the considerable discussion on whistle-blowing, it is rare to find an exact definition. The first time 'whistle-blowing' was used was in 1963 in the case of Otto Otopeka (2). He gave classified

documents on security risks in the new US administration to the chief counsel of the Senate Sub-committee on Internal Security. The Secretary of State, Dean Rusk, dismissed him from his job in the State Department for conduct unbecoming an officer. Alternative terms may be conscientious objector (3), ethical resister (4), mole or informer (5), concerned employee (6), rat (7) or licensed spy (8).

My own definition is: "The unauthorised disclosure of information that an employee reasonably believes evidences the contravention of law, rule or regulation, code of practice, or professional statement, or that involves mismanagement, corruption, abuse of authority, or danger to public or worker health and safety."

The lack of authorisation can apply to internal and external whistle-blowing. The internal variety refers to bypassing the normal managerial hierarchy such as one's immediate boss, or reporting to another department or to a general manager when there are other available channels. This variety is open to manipulation and suppression. External whistle-blowing refers to going to those outside the organisation – the media, a member of Parliament or a professional body. It indicates a serious breakdown of communication between employer and employee and may lead to dismissal.

The legal situation

Does the law side with the whistle-blower or with the employer? English law has an implied common law duty not to misuse confidential information belonging to the employer and this duty may continue after the employment has finished. Since there are practical problems in taking legal action against ex-employees, the employer's best option is to seek from employees an express restraint clause.

An exception is made when disclosure is in the public interest. In the 1968 case of Initial Services Ltd vs Putterill, in the UK, Putterill had resigned as sales manager and then handed to the *Daily Mail* documents providing details of an unlawful price protection ring involving the employers, and of price rises attributed to employment tax in order to disguise higher profits. Lord Denning held that the public interest exception to the duty of confidence extended to

"...any misconduct of such a nature that it ought to be disclosed to others... The exception should extend to crimes, frauds and misdeeds, both those actually committed as well as those in contemplation."

The only legislation to support whistle-blowing concerns oil rigs (9), the Offshore Safety (Protection Against Victimisation) Act 1992. Offshore workers dismissed for raising valid concerns could now make a complaint of unfair dismissal to an industrial tribunal.

The law: whistle-blower protector?

Is the law on the side of the whistle-blower? A series of stringent filters need to be passed for the public interest defence to be upheld. Some of these:

- There were serious misdeeds or serious public harm.
- The whistle-blower acted reasonably and in good faith.
- The information should be communicated to an appropriate recipient. (Who is an appropriate recipient remains unclear.)
- The way in which the information was acquired was not more of a threat to the public than the value of what was revealed.

Is the way ahead unproblematic? Again, the answer has to be 'No'. Apart from the ambiguities and crudities of employment law, there are practical aspects. In 1973, in the wake of a number of well publicised hospital scandals to which attention was drawn by whistle-blowing, the Committee on Hospital Complaints Procedure, chaired by Sir Michael Davies, added realism: "We have never had any doubt that in the hospital service the investigation and satisfaction of complaints is primarily a function of management. But in the past there have undoubtedly been occasions when management has not discharged this function... It would be unrealistic to suppose that there will never be breakdowns in the future."

Despite this recognition, the path of the whistle-blower is never easy (10-14). Conduct and character come under scrutiny and many begin to wonder that the matter seems to have been turned on its head with the whistle-blower now in the dock. The whistle-blower may find that the normal courtesies of the organisation have been withdrawn and every infraction of rules and procedures, howsoever petty, is acted upon.

The trouble with whistle-blowing is that there is plenty through which to blow. Gerald Mars shows that occupational crime, sometimes referred to as 'part-time crime' (15) is an accepted part of everyday jobs (16). Covert rewards are so intimately connected with some occupations that it is impossible to understand sections of the economy without reference to them. It is necessary to be highly selective to avoid becoming a professional full-time whistle-blower.

In a survey of 87 American whistle-blowers from the civil service and private industry, all but one experienced retaliation, with those employed longer experiencing worse reprisal. Harassment came from peers as well as superiors and most of those in private industry and half of those in the civil service lost their jobs. Of the total, 17 per cent lost their homes, eight per cent filed for bankruptcy, 15 per cent got divorced and 10 per cent attempted suicide (17).

A similar result emerged from a six year long US study of 64 whistle-blowers, ethical resisters who felt impelled to speak out because they had witnessed a serious violation of legal and ethical standards. Most were in their 30s or 40s and were conservative persons devoted to their work and organisations. They had built their careers by conforming to the requirements of bureaucratic life. Most had been successful until they were asked to violate their own standards of workplace behaviour. Whistle-blowing resulted in economic and emotional deprivation, disruption of careers and personal abuse (18).

There could be few instances more tragic than that of Stanley Adams, a former executive with the Swiss pharmaceutical manufacturer Hoffman La Roche. Adams was imprisoned under Swiss law for exposing, in 1973, the company's illegal price-fixing methods to the European Commission. His wife's probable suicide, the financial ruin of the family and lack of support from the European Commission are portrayed in the film *Song for Europe*. With an ironic twist, Adams was arrested at Bristol railway station in 1993 for plotting to kill his new wife.

Not all favour whistle-blowing. Peter Drucker views it as 'informing' and shows that western societies that encouraged informers were bloody and infamous tyrannies – Tiberius and Nero in Rome, the Inquisition in the Spain of Philip II, the French Terror

and Stalin. Drucker feels that there is no mutual trust, no interdependency and no ethics when whistle-blowing prevails. Milton Friedman is also of this school of thought. Their views have not gone unchallenged. But informing is itself a value-laden interpretation, not a neutral description, of whistle-blowing. It is by no means self-evident that whistle-blowing is informing and Drucker offers us no support for his claim. Such support requires as its basis rigorous normative reflection, and it is reflection of this kind that is precisely the province of business ethics (19).

It can be argued that evading questions about the ethical implications of one's actions constitutes moral negligence (20). Sound ethical thinking must be based on as full an understanding of a situation as it is possible to obtain and there is also a need to consider unintended or undesirable consequences of decisions (21). Any view of life that stops short of a rigid totalitarian attitude must make allowances for the legitimacy of individuals asserting alternative moral standpoints and occasionally, in extremes, blowing the whistle. There are comparisons between whistle-blowing and civil disobedience (22). A text on strategic management includes a chapter on business ethics and suggests that whilst thoughtless observers may criticise whistle-blowing as squealing, in fact, any enforcement of law and ethics must rely partly on whistle-blowers. Public good emanates from whistle-blowing. The problems with the cargo doors on DC-10 aircraft in the 1970s were highlighted thus (23).

A procedural point over which whistle-blowers need to take particular care is that when they report abuse, there is no delay in making the report. Trained members of the staff whose responsibilities include the reporting of such incidents are likely to face disciplinary action themselves if their reports are made long after the abuse.

The outcome

Even assuming near saintliness and a cast-iron psychological constitution capable of withstanding considerable pressures on self and family, there remains the question as to what exactly will be the outcome of whistle-blowing.

An industrial tribunal can order an employer who has wrongfully or unfairly dismissed or victimised an employee to compensate the employee for his losses. Awards are low in relation to the economic harm and damage to career suffered and rarely exceed £ 2, 500.

Reinstatement can be ordered but this actually occurs only in about one per cent of cases. The reason is that relations between the employer and the whistle-blower have invariably deteriorated to the extent that it is easy for the employer to convince the tribunal on the impracticality of reinstatement. The employee too is usually not willing to re-enter a hostile work environment.

Case studies

Ken Callanan, student nurse in a psychiatric hospital, reported a charge nurse for constantly abusing patients. Callanan was discriminated against by management, other staff and the trade union. Forced to resign by such behaviour, he received compensation in a tribunal for constructive and unfair dismissal.

Dr Helen Zeitlin appealed successfully at a special hearing at the Department of Health in London against her redundancy, which came on the heels of her comments at a public meeting about inadequate resourcing of certain services in her health district in Redditch.

Dr Chris Chapman, biochemist at the Leeds General Infirmary, exposed fraud relating to medical research and additional waste of public money. He was sacked the day before his 50th birthday to avoid paying him pension. He was re-instated following his legal victory.

Desmond Smith, a black health visitor, won damages of £ 27,000 against the racism of which he complained in his health authority.

Utilising the services of whistle-blowers

Whistle-blowers can act on faulty perceptions. A few manipulate to their advantage after being justifiably accused of a disciplinary offence. This counter-attack is the converse of a tactic often adopted by employers against their whistle-blowers. Research shows that most whistle-blowers are not habitual troublemakers. Rather, they are of the type that forms the bedrock of any organisation. Devoted, loyal and, if anything, conservative, they are spurred to blow the whistle only by intense disquiet on witnessing unethical action.

The best approach is for the institution to invite comments, observations and criticism with proof to back the statements made. Managers with foresight will ensure that they learn about nasty problems in their organisations before these stories hit the media by setting up hotlines and encouraging employees to use them (24). The US has passed Whistle-blower Protection Acts for the public sector with a compensation fund of up to $500,000 per individual. This country recognises that whistle-blowers have an important contribution to make. They can save lives and increase efficiency and effectiveness.

A code of ethics for whistle-blowers

Norman Bowie lists his requirements of justifiable acts of whistle-blowing:

- The whistle-blowing stems from the moral motive of preventing unnecessary harm to others.
- The whistle-blower has used all the available internal procedures for rectifying the problem before making public disclosure. (This may be precluded under certain special circumstances.)
- The whistle blower has "evidence that would persuade a reasonable person."
- The whistle-blower perceives serious danger from the violation.
- The whistle-blower acts in accordance with responsibilities for "avoiding and/ or exposing moral violations."
- The whistle-blower's action has reasonable chance of success. (25)

Others have suggested practical points to ponder:

- How comprehensive is the worker's knowledge of the situation? Is the worker's information accurate and substantial?
- What exactly are the unethical practices involved? Why are they unethical? What public values do these practices harm?
- How substantial and irreversible are the effects of these practices? Are there any compensating public benefits that justify these practices?
- What is the employee's obligation to bring up such practices by working within the organisation or by going outside it? What probable effects will either alternative have on the company's practices? On society? On the firm? On the employee? (26)

Sisela Bok sees three cascading levels of conflict: Is whistle-blowing in the public interest? The professional ethic requiring collegial loyalty clashes with responsibility to the public. Third is the fear of retaliation (27). Jenson asks whether the whistle-blower has a low tolerance for shortcomings and asks how often and with what intensity does one blow the whistle (28). Jenson also contrasts one's obligation to the organisation and colleagues with that to the profession, the family, oneself, the general public and to basic values such as truth, independence, fairness, cooperation and loyalty.

The Government Accountability Project in Washington, DC, has produced a survival guide for whistle-blowers which states: "A well planned strategy has a chance of succeeding but unplanned or self-indulgent dissent is the path to professional suicide."

Whistle-blowers may never have it easy. Career mortality and occupational morbidity should be maintained at the lowest possible level. Positive whistle-blowing should be recognised as being intended for the general good. Increasing awareness of health ethics will improve the quality of debate and action.

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Communication

Communication is the vital link between the doctor and patient and between doctors. It can make or break a relationship. Difficult situations in clinical practice call for good communication as well as empathy. Good doctors develop this trait, which patients often call 'good bedside manners'. Unfortunately, this tool for success in clinical practice does not find a place in medical schools today and students are deprived of role models. So most learn to communicate through the expensive school of experience or do not learn at all. This void is apparent when doctors speak to the media, write articles or have to speak in lay parlance. Poor communication has been the single most common reason for doctors being prosecuted under the Consumer Protection Act in India. In a litigious world, the fact that doctors speak ill of other doctors instigates patients to decry the medical profession and sue their physicians. A doctor's communication skills are put to the test while breaking bad news to the patient or relatives. With increasing specialisation and fragmentation of medical practice, the traditional role of the general practitioner as communicator and friend of the family has gradually been eroded. Alternative medicine has seen a resurgence despite technological advances, as it caters to patients' need for holistic health care. This selection of articles tackles some of these issues.


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Informed consent in public hospitals

S P Kalantri

A medical teacher and physician at a community hospital reflects on the fact that communication takes a backseat in busy public hospitals. This essay describes the problems of seeking informed consent in the Indian setting. Doctors are not trained to respect patients' autonomy. The problem is compounded as public hospitals are usually used by the very poor and doctors' patronising behaviour reinforces class hierarchies. As doctors in such settings are almost always viewed as God, they are reluctant to institutionalise the procedure of seeking informed consent. They choose instead to treat questions from patients as signs of a lack of trust, and threaten to discontinue treatment. The article also discusses practical difficulties such as improperly designed forms, inadequate training, and the dearth of good role models. The discussion is contextualised within the larger problems affecting the system, such as cultural differences between provider and patient, scarcity of resources, and a working environment that does not allow space for ethical practice to develop. A question worth exploring further is that of systems of accountability. Doctors should not view informed consent as a simple defence against potential litigation.

Informed consent is a commendable concept: it gives patients the power to participate in decisions concerning their own management, to a greater degree than ever before. The qualifying adjective is superfluous (1), for the word consent (*cum*, 'together', and *sentire*, 'to feel' or 'to perceive') clearly implies sharing of information. Patients do have problems understanding the nature of their illness and management plans. It is the duty of the doctor to ensure that the patient is helped to make a rational decision.

What do patients want? The priority is honest, unbiased, up-to-date information about their illness, its likely outcome, and the risks and benefits of different interventions. They also want help to identify and secure their treatment preferences. When uncertainty

exists they want a full and frank discussion without omissions or glossing over, and advice explicitly supported by the best available evidence (2).

What doctors feel about informed consent

I asked several doctors what informed consent meant to them. Most disliked the very concept of informed consent and considered it an obligatory legal formality forced on them by the Consumer Protection Act. Their arguments were:

- Informed consent breeds suspicion and mistrust. Patients are uncomfortable with doctors who merely give them options and ask them to choose one. Our patients want us to take responsibility and not shift it onto their sagging shoulders. If we do not act on their behalf, we might be accused of dodging duty.
- Patients fail to understand our misplaced emphasis on consent forms. Our patients have full faith in our knowledge, skills and competence. Are we not capable of choosing the best treatment for them?
- Informed consent seriously erodes the doctor-patient relationship. Openness and frankness make patients anxious, reluctant and distressed.
- How do we share information during an emergency? Can patients respond appropriately during a crisis? Can patients weigh the pros and cons of a treatment and make a logical decision?
- Informed consent is an intellectual exercise for armchair ethicists. The emphasis on autonomy and equality is misplaced and lacks knowledge of practical difficulties.

Doctors love to patronise and dominate. Their arrogance and indifference to the philosophy of informed consent is widely known. Medical and public fora have passionately debated these issues. Surprisingly, most residents and doctors in teaching public hospitals tacitly endorse such reservations against information sharing. To most of them getting informed consent is a needless nuisance, to be delegated to a raw resident whose sole responsibility is to get the patient's signature on the dotted line.

A few exceptions apart, public hospitals sorely lack good quality information leaflets or audiovisual material to disseminate information to their patients. Residents working under tight time

constraints find it impossible to explain procedures to the patient. Nor are they sufficiently motivated to do so, for providing explanations and sharing information bring no tangible rewards. No attempt is made to ensure that the appropriate type and amount of information has been provided and the patient has understood the procedure.

Any query or request for an explanation meets with stern disapproval and arouses a characteristic, callous response from the resident: "If you don't trust us, you had better leave the hospital." The resident, always in a tearing hurry, lists all possible risks (death gets cruelly emphasised) and disappears before the patient can absorb the blow.

Consent forms in most hospitals are either too brief or sketchy, or full of incomprehensible medical and legal jargon. They carry hastily scribbled, badly worded, and at times illegible, text. The text is seldom read aloud to illiterate patients, who, being unable to decipher the draft, simply leave their thumbprints on the case sheet. Seldom do they get the opportunity and time to understand the intervention. The nagging fear that not signing the consent form might amount to incurring the displeasure of the treating doctor weighs heavily on their mind.

Insensitive forms

I reproduce below a consent form obtained in a busy surgery ward of a teaching public hospital:

"I am suffering from a strangulated intestinal hernia. I need immediate surgery to save my life. I also have mild hypertension. I shall be operated on under general anaesthesia. I run a high risk for surgery. I might develop life-threatening complications during anaesthesia. My surgery might lead to some complications, which could kill me. After surgery I might run into problems, which are well beyond the surgeon's control. In spite of all these risks, which have been fully explained to me, I agree to undergo surgery. Should anything go wrong, neither doctors nor nurses shall in any way be responsible for an adverse outcome. The responsibility shall be entirely mine."

What makes taking consent so insensitive and crude? I picked up, at random, several residents from a teaching public institution

and asked them if they were ever taught how to obtain a patient's informed consent. Most sheepishly admitted their ignorance. To some of them, consent was a legal vaccine that reduced the risk of litigation. Many residents were conscious of their lack of communication skills: an inability to use simple words in patients' regional languages left many of them tongue-tied at the patient's bedside. They were not getting across to their patients, but could do nothing about it.

Dr Franz Ingelfinger's two-decade-old description (3) seems to come straight from one of our busy wards:

"Even if a physician takes pains to use appropriate language, he may still lack empathy if he is not acutely sensitive to the emotional needs of the patient seeking consultation. Distraught by anxiety, fear and perhaps suspicion, the patient hears the sounds but not the meaning of words; reassurances that cancer is an unlikely diagnosis and a barrage of tests to prove this point may convince the patient that the opposite is true. 'We shall not need another operation' is recorded in the patient's mind as 'another operation'. Advice that anti-hypertensive drugs or insulin are in order, possibly for a lifetime, may give the patient an idea of incurability. Even advice on smoking and overeating may elicit negative instead of positive results in the susceptible."

Today's role models

To whom should residents turn to pick up the art of communication? Teachers? (4) Most residents expressed gratitude to their teachers for teaching them the art and science of modern medicine, but said that apart from a few exceptions their teachers were poor role models for learning the ethics of the doctor-patient relationship. Medical teachers, said several residents, are generally stiff-lipped and discourteous when patients seek information. Students tend to imbibe their teachers' arrogance and ill manners during their impressionable years and subconsciously emulate them in their professional practice. And, as a resident asked in exasperation: "Where are good role models left in medical colleges now?"

Residents welcomed the idea of learning communication skills and behavioural sciences. Several suggestions emerged during discussions: Had we been taught how to talk with patients and

what to say (5) during our clinical postings, we would have felt more comfortable with our patients. Many thought that introducing medical ethics in the undergraduate curriculum (6) would help them be more humane, sensitive and responsive to patients' needs. Few thought that they should have also been taught how to discard a patronising attitude and get more interactive with patients.

There were some discordant notes too. A resident asked me: "Most rural patients attending public hospitals do not insist on an intensive, informative discussion. Their main priority is to get cost-effective treatment. Could we make use of their trust in us and practise a bit of paternalism and dominance? What is the evidence that published (western) guidelines for getting informed consent are equally valid in our setting? Could we find ways to make consent more accessible, acceptable, tangible and practical? More patient-friendly and less legalistic?"

A senior medical teacher, who is deeply respected in the rural community for his compassionate and committed approach, shared his residents' concerns. A patient must know his disease and management plans, he agreed, but then should entrust the responsibility of taking the final decision to his doctor. How can a doctor-patient relationship flourish in an atmosphere where autonomy and equality overrule trust and faith? A quest for information might make patients more knowledgeable, but it would also render them insecure and indecisive.

He quoted Charaka: "No gift is greater than the gift of life. The patient may doubt his relatives, his sons and even his parents, but he has full faith in his physician. He gives himself up in the doctor's hands and has no misgivings about him."

The teacher admitted honestly: "I might continue to treat inquisitive and sceptical patients – and their tribe is rapidly increasing thanks to the internet – but my heart won't be there in their management."

Teaching tomorrow's doctors

Neither teachers nor residents nor patients seem to know how to handle the issue of informed consent without anguish. Let us concentrate on residents, the future consultants. How can they be helped? Could communication techniques taught in classrooms ease

their burden? Or should students passively imbibe these skills from their mentors and patients as life moves on? There are no easy solutions. Nor can there be cut-and-paste shortcuts for information sharing and obtaining consent.

As Dr Ingelfinger (3) summed up years ago: "In medical schools, a student is told about the perplexity, anxiety and misapprehension that may affect the patient as he enters the medical care system, and in the clinical years the fortunate and the sensitive student may learn much from talking to those assigned to his supervision. But the effects of lectures and supervision are ephemeral and are no substitute to actual experience."

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Ethical dilemmas in breaking bad news

K M Mohandas

In the Indian context, patients often seek care for an advanced cancer, with consequently higher morbidity and mortality. Many also believe that cancer is inevitably fatal. And desperate patients often go "doctor shopping," viewing medical care as a commodity. Many of them take recourse to indigenous medicine.

This article was written when the discipline of medical ethics was just beginning to develop in India. A gastroenterologist speaks candidly about the difficulties he faces in breaking bad news to his cancer patients. It reflects the clinician's struggle to apply ethical principles in daily practice. With little formal training available on the essential skill of communication, the author documents his own practise. He adapts his procedure to suit the patient's character and needs. He emphasises the role of collective decisions involving the family, rather than the individual alone.

Introduction

One of my concerns after joining a cancer hospital was the manner of conveying the diagnosis to the patient with cancer. Most of us receive little formal training on this aspect of medicine during undergraduate and postgraduate training. All I can recall is telling the relatives of patients with acute myocardial infarction or stroke of a 25 per cent possibility of death.

Observing the approach of colleagues has been of little help. Some colleagues embark on a very positive approach, giving the patient and relatives hope (albeit false) and believing that the patient is blissful in his ignorance. Others take a middle path and explain all the facts to the relatives while keeping the patient in the dark. Few explain at length the diagnosis, stage of cancer, options on treatment,

side effects, financial burden and short- and long-term prognosis. Thereby they upset some patients and families.

Keeping the diagnosis from the patient

"Please do not tell the patient that he has cancer," is a frequent request made to me by relatives. I recently came across a situation where the relative who accompanied and then looked after a bachelor patient with terminal cancer kept the patient and other relatives in the dark and managed to change the patient's will before his death. Many factors such as illiteracy, ignorance, misconception, superstition, domestic and social problems, fatalistic attitudes and other prejudices add hurdles to the information process. Patients returning with recurrence or progression of disease complain about the lack of proper information during the primary treatment. I have realised that there is no simple solution.

Osler cautioned those dealing with fatal illness: "It is not for you to don the black cap and assuming the judicial function, take hope away from any patient...hope that comes to us all." Unfortunately, several medico-legal and ethical factors make us don the black cap.

Relevant issues

The first issue concerns the confidentiality of the doctor-patient relationship. Can the doctor discuss the illness with the relatives and friends who accompany the patient, without first telling the patient about his disease and obtaining his permission to tell others? Second, because of the Consumer Protection Act and the high cost of investigating, treating and supporting patients with cancer, should we not inform the patient fully about the disease, the benefits, complications and economic costs before he signs the consent form? Third, many cancer therapies are still experimental and can be provided only in the setting of a clinical trial. Bearing in mind the ethical aspects of experimental therapies, a fully informed, written consent needs to be obtained. Would not informing the brave ones lead to selection bias in studies? Fourth, many patients with advanced disease have already been told the nature of their illness and come for a second verdict with lots of hope.

Attitudes towards cancer

In India, the fear and hopelessness engendered by the diagnosis of cancer is very strong and is often based on hearsay or anecdotal experience of relatives or friends. The degree to which people are adversely affected by the diagnosis of cancer is related to the individual's ability to adapt and come to terms with thoughts and feelings focused on their own mortality and altered body image.

In the West, some are unhappy with the diagnosis of cancer but most surveys indicate that the majority of patients seek more information from their doctors. Although the number of doctors in the West who shy away from disclosing the diagnosis of cancer to their patients has decreased, there are many who genuinely believe that what the patients do not know will not harm them.

The convenient practice would be to give information only to those patients who actively seek it. The ideal balance between frankness and details that may provoke is not universally established, nor is it the same for all patients. In cancer, more than in any other illness, the dynamic view emphasises the beneficial effect of participation by the patient in the outcome of therapy.

For many cancers there are no standard treatments and for many others different therapies provide similar results. Furthermore, conflicts of interest between various specialists (surgeon, chemotherapist, radiotherapist) result in raising hopes beyond those justified by the facts.

Possible solutions

The specialist-dominated, often autocratic approach to cancer treatment, the standard pattern in the 1960s in the USA and the UK, has undergone a change to a more open dialogue where the patient and physician are equal partners in decision-making. A multi-dimensional approach is required to meet physical, psychological, social and spiritual needs.

The need for specific information varies between patients. In general, patients wish to be well informed about the diagnosis, therapeutic options, side effects and outlook. Some prefer details. Others are content with limited information. Still others prefer to have the possibilities of complications minimised or blunted.

Breaking bad news therefore requires skills in communication and an understanding of the patient's mind and preferences.

We can take a cue from screening for AIDS and counsel all those who are afraid to face the diagnosis of cancer. Since up to 75 per cent of patients with cancer in the West seek alternative therapies that offer hope, another approach may be to provide non-conventional therapy under the same roof.

Once I have identified the brave ones after a few meetings, I prefer to talk directly to them. For those who are scared, I disclose the news first to the spouse or an adult son or daughter. As rapport builds up during therapy more information can be provided directly to the patient. Unfortunately, many patients with advanced disease come for a single consultation when palliation of symptoms is only therapy. Should we tell these patients the bitter truth? I follow Ambroise Pare's advice: "Always give the patient hope, even when death seems at hand." I believe that if your time has not come, even your doctor can't take you away.

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When the patient wants to try another system of medicine

G D Ravindran

Indigenous systems of medicine have existed for centuries in India. Today they are viewed as 'alternative' to western allopathic medicine. The relationship between these different systems, and between the respective practitioners, has often been one of conflict and distrust. An added problem is the large number of bogus claims for miracle cures which mislead patients. In this essay, the author, a physician, suggests guidelines based on his experience of dealing with patients who wish to use different systems.

Complementary or alternative systems of medicine are being practised all over the world. In our country, we have a long tradition of alternative systems of medicine, such as ayurveda, unani and homeopathy, which are recognised by law and the government. In addition, we also have newer, novel therapies such as ozone therapy and magnetic therapy. Our patients tend to try these systems when they have chronic illnesses or when they do not get relief from the allopathic system.

As practitioners of allopathic medicine, we face many ethical dilemmas when we are confronted with patients who wish to try alternative systems of medicine. This essay explores these dilemmas and the ethical issues involved.

For many chronic conditions, allopathy has no cure or offers only palliation to the patients. In such circumstances, patients resort to alternative systems of medicine. Often, they ask the doctor's advice. An allopathic practitioner may not have knowledge of other systems. Hence he is not in a position to give advice regarding the therapy. It would be perfectly ethical for him to say that he does not know about the therapy and that the patient has to make the choice.

There are two ethical principles involved in this response. The first of these is the need for not deceiving others. Alternative systems of medicine may have an answer to the patient's problem. By not

allowing the patient their benefit, the practitioner is deceiving the patient through his ignorance.

Other ethical elements involved are the virtues of compassion, honesty and humility. When a patient is suffering and allopathic medicine cannot offer much relief or a cure, it is compassionate on the part of the practitioner to allow the patient to try alternative systems of medicine. A practitioner practises the virtues of humility and honesty when he agrees to the patient's requests because he accepts that his knowledge and skills are limited.

Just as there is a right not to deceive there is also an obligation on the part of the practitioner to see that his patient is not deceived when he undertakes an alternative system of medicine. If a practitioner has the knowledge that a particular treatment is useless and would be a financial drain on the patient's resources, it is the practitioner's duty to inform the patient accordingly.

For example, many alternative systems of medicine profess to have a cure for AIDS. Some patients who have undergone these therapies have spent money and in the end suffered and died. If the practitioner has this prior knowledge and if a new patient asks about such therapies, a practitioner should have no hesitation in advising against the therapy.

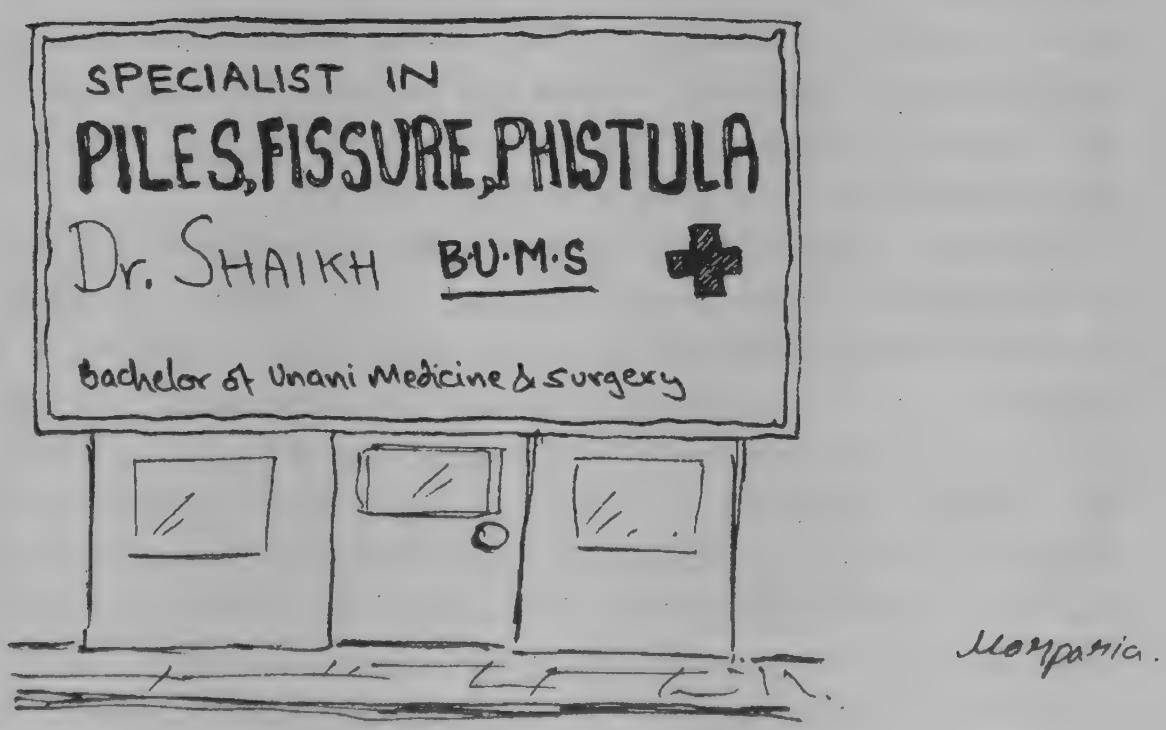
Very often, patients ask their doctors whether they should discontinue allopathic therapy when they try alternative systems of medicine. The answer to this question depends on the situation. If there is a definite cure and there is a public health hazard if the patient is not treated then a practitioner should strongly advise the patient to discontinue the medications. For example, in TB there is an effective cure and non-treatment could lead to the spread of infection in the community. Here the ethical principle involved is that of beneficence. The practitioner is acting for the good of the patient while protecting the rights of uninfected persons not to be infected. Practitioners also have a duty to the community. When the allopathic therapy is beneficial for patients, my advice would be to continue both treatments, for example insulin in NIDDM patients.

Patients may try alternative systems of medicine and return to allopathy when they find the alternatives useless. What should practitioners do? Twenty or 30 years ago practitioners would refuse

to treat such patients since they had refused to practise what was ordered.

We have come a long way from that paternalistic model of the patient-doctor relationship. Nowadays most practitioners come to a shared understanding with the patient about his therapy. Many physicians will berate such patients and treat them again as if nothing has happened. Here they exhibit the virtue of tolerance. The patient's experience also enhances the practitioner's knowledge about the efficacy of the alternative therapy and its side effects, enabling him to give better advice to the next patient who asks about such therapy.

Can a practitioner refer a patient to a practitioner of an alternative system of medicine? The code of medical ethics of the Medical Council of India does not permit it. The code states that a practitioner should not associate with a person who does not practise medicine on a scientific basis. As the scientific basis of many of the alternative systems of medicine is not known, a practitioner should not refer a patient to an alternative system of medicine.



Iatrogenic error and truth telling: a comparison of the United States and India

Shishir Maithel

It is not uncommon for health care professionals to make mistakes. All physicians and many lay people are aware of this fact. But it is difficult to openly discuss the subject because of the aura of infallibility that often surrounds physicians and medicine. This paper is among the first pieces of empirical research published in the journal. The writer captures the views of Indian and American doctors on the question of telling a patient that they made a mistake. We learn, rather to our surprise, that similar attitudes and problems exist among both sets of doctors – a lack of training, concern about litigation and a common understanding of ethical practice.

At the core of the doctor-patient relationship is a feeling of trust between the two. If a patient does not trust his/her physician, then the physician's effectiveness is greatly compromised. Patients must know that their physicians have their best interests in mind and are telling the truth about their illness and progress. The physician is also ethically obliged to report the truth to the patient, the exact extent being debatable among different cultures.

The history of literature on medical truth telling dates as far back as 1803 when Thomas Percival wrote: "to a patient who makes inquiries which, if faithfully answered, might prove fatal to him, it would be a gross and unfeeling wrong to tell the truth." (1) This view can be contrasted with, for instance, that of Saul S Radovsky who writes: "doctors are not wise enough to tell in advance who should not be told [and] that shielding is ultimately impossible and that the price of its temporary achievement is an enduring sense of betrayal. Once lied to, even supposedly in their own interest, people will not trust fully again." (2) The trend, from withholding information to telling the truth, is supported by surveys which show

that in 1985 at least 70 per cent of physicians believed in telling patients about their cancers as opposed to 12 per cent just 24 years ago (2). It is safe to say that most people want their doctors to tell them the truth. The only concern is the manner in which it is disclosed. As Norman Cousins writes, "The real issue is not whether the truth should be told but whether there is a way of telling it responsibly. Certainly it should not be allowed to become a battering ram against the patient's morale, impairing his ability to cope with the greatest challenge of his life."(3)

One subject of much discussion is whether or not to reveal iatrogenic error. Many physicians are reluctant to inform their patients of their mistakes. In a study of house officers in the US, the patient and/or family was informed of the mistake only 24 per cent of the time (4). Patients, on the other hand, want to be told of any mistakes. In another study, 98 per cent of the patients surveyed "desired or expected the physician's active acknowledgement of an error." (5) Legal concerns, such as fear of a lawsuit, are considered to be a major reason for physicians withholding information from their patients. However, the same study found patients nearly twice as likely to report or sue their physician if they discovered the mistake independently (5). Thus, it may be in the physician's best interest to just tell the truth.

There is no universal standard for truth telling. The exploratory study reported here compares the Indian and US systems, specifically on the issues of whether iatrogenic error affects treatment decisions and how mistakes are handled. I expected that fewer Indian physicians would choose to resuscitate a terminally ill patient who suffers a cardiac arrest, and fewer Indian physicians would choose to disclose an error to the patient and /or family.

Methods

A questionnaire was distributed to convenience samples of physicians in New Delhi, India, at the Indraprastha Apollo Hospital outpatient department, and in the United States at the University of Chicago Hospitals in Chicago, Illinois.

The questionnaire opened with a clinical case vignette, based on a model developed for another study by Dr David Cassarett, which presented the physicians with three possible scenarios:

- A 75-year-old, terminally ill patient suffers a cardiac arrest.
- A 75-year-old, terminally ill patient suffers a cardiac arrest as a result of an *unknown* allergy to a prescribed antibiotic.
- A 75-year-old, terminally ill patient suffers a cardiac arrest as a result of *a known (by the physician), but forgotten,* allergy to a prescribed antibiotic.

In each case, the physician is asked whether or not he/she would resuscitate the patient.

This case vignette is designed to reveal any differences in resuscitation decisions when the cardiac arrest is due to iatrogenic error.

The second part of the questionnaire addressed issues such as:

- Who is informed when a mistake is made?
- Are there any legal issues that are of concern when revealing iatrogenic error?
- Was any training received in medical school on how to handle mistakes?

Results

Physicians at Indraprastha Apollo Hospital in New Delhi, India

Of a total 86 Indian physicians available, 41 were approached and 40 complete questionnaires were obtained. Their ages ranged from 28 to 60 (mean = 41) years old, and the number of years in practice varied from one to 36 (mean = 14) years. 82.5 per cent of the surveyed physicians were male. Thirty-four had received a majority of their training in India while six received it in Britain. The majority of physicians were specialists in internal medicine.

When asked whether they would resuscitate a terminally ill patient, with at most a few weeks to live, who suffers from cardiac arrest (scenario 1), 55 per cent responded that they 'certainly' or 'probably' would. However, when the cardiac arrest resulted from an unknown allergy to a prescribed antibiotic (scenario 2), the percentage increased to 87.5 per cent. When the allergy was known, but merely forgotten by the physician (scenario 3), the percentage who would resuscitate climbed to 95 per cent, which is all but two physicians.

There was no significant difference between scenarios 2 and 3, suggesting that the physicians were assuming similar responsibility

when the allergy was unknown (scenario 2) and when they forgot about the allergy (scenario 3). This may imply that the physicians considered the cardiac arrest to be iatrogenic in both scenarios 2 and 3. The most popular explanation provided by the physicians in their responses was that they were ethically bound to resuscitate and felt a sense of moral duty when the cause of cardiac arrest was iatrogenic in nature.

The next question was if there was an office to which they should report a medical error. Twenty-three (57.5 per cent) responded that no such department existed. Of the 17 physicians who said that there was such a department, a variety of answers including "the director of medical services" were given when asked to name the office.

Seventy-five per cent of the physicians practising in India responded that they would report an error to the patient, and 72.5 per cent said they would report to the patient's family as well. The most common reason for disclosure expressed by the physicians was their sense of ethical duty to be honest with the patient and family. The second most popular reason was that the physicians wanted to discuss the possible complications resulting from the error. Only five physicians would not reveal an error to a patient and five said that it depended on the situation. Thirty-six physicians, or 90 per cent, expressed some concern for legal issues when revealing an error. Because of the recently passed Consumer Protection Act in India, 27 physicians specifically mentioned their fear of a lawsuit.

Sixty-five per cent of the physicians had not received any instruction in their medical training on how to handle a mistake, which interestingly included all six physicians who had received a majority of their training in Britain.

However, when asked to whom a physician is obliged to report an error, the three most common responses were: hospital authorities; patient and family, and the medical director or senior physician in charge. Shockingly, 87.5 per cent of these physicians felt this 'almost never' happened, and if it did, only 'less than half' of the time.

Physicians practising at University of Chicago Hospitals in Chicago, Illinois, USA

Fifty-three physicians were approached at the University of Chicago Hospitals, and 40 completed surveys were obtained. The age of the physicians ranged from 26 to 75 (mean = 38) years, and the number of years in practice ranged from 1 to 40 (mean = 9.5) years. Sixty per cent of the physicians surveyed were male. The majority of physicians were specialists in internal medicine. Thirty-six received a majority of their training in the United States, one received it in India, and three studied in other countries.

When asked about scenario 1, 50 per cent said they 'certainly' or 'probably' would resuscitate the patient. The percentage increased to 82.5 per cent for both scenario 2 and scenario 3.

Again, there is no difference between the results of scenarios 2 and 3. The physicians expressed an obligation to resuscitate the patient, especially when the cause of the cardiac arrest was iatrogenic in nature.

Eighty-five per cent (34 physicians) of the US physicians said that there was an office to which to report medical errors, and an overwhelming majority of them agreed that it was the medico-legal (risk management) department.

Ninety per cent (36 physicians) said that they would report an error to the patient, and 75 per cent would reveal the error to the patient's family. As with the Indian physicians, a sense of moral duty to be honest with the patient and family was the motivation. The decrease in percentage to reporting to the family may be explained by the opinion of some physicians that it is the patient's decision whether or not to tell the family. Thirty-four physicians, or 85 per cent, expressed some concern for legal issues when disclosing the error. Of these, all but two specifically mentioned the fear of a malpractice lawsuit.

Fifty per cent of the physicians said their medical training did not include instruction on how to handle mistakes. However, when asked to whom a physician is obliged to report an error, the majority agreed that the patient should be informed. Compared to the 87.5 per cent of Indian physicians, only 52.5 per cent of the US physicians felt that this rarely or almost never happened.

Conclusion

Except for two of the survey questions, the responses of the Indian and US physicians did not differ significantly.

One difference was when the physicians were asked whether or not an office or department existed in the hospital to which to report a medical error. Twice as many US as Indian physicians said that such a department existed.

The second major difference was in how often physicians in the two countries felt medical errors were reported. In India, 87.5 per cent of the physicians felt that it happened 'less than half' of the time to 'almost never', compared to 52.5 per cent of the US practising physicians.

Discussion

The similarities in the responses of two groups of physicians are striking and unexpected. This study was conducted with the expectation that physicians in the US would be more likely to resuscitate than those in India, mainly because the US has more resources and its legal system encourages resuscitation. It was also believed that in India, physicians would be less likely to resuscitate a 75-year-old, terminally ill patient because of cultural or spiritual beliefs. In fact, the actual percentages of resuscitation were higher, though not significantly so, for the Indian sample.

It was also believed that the US emphasis on having informed patients and the emphasis on truth-telling as a part of ethical medical practice would encourage US physicians to disclose errors to the patient and / or family.

However, similar percentages of Indian and US physicians responded that they would discuss the error with the patient and/or family. The Indian physicians also had the same legal concerns and a similar percentage had received training on how to handle mistakes.

This exploratory study thus serves to point out similarities between the two countries. One cannot assume that a developing county with limited resources will differ in every aspect when compared to a rich country. The results suggest that at least these two samples

of physicians have a common mentality and protocol when dealing with iatrogenic error and truth telling.

However, the significant differences mentioned suggest that the Indian medical system is not as prepared and equipped to handle legal affairs as is the US medical system. In the United States, malpractice suits are common. Thus, the University of Chicago Hospitals have invested the time, money, and man-power to create a department to handle legal affairs and protect physicians. Physicians are aware of this support, perhaps encouraging them to say that the proper authorities or people are informed of a medical error. However, malpractice suits are relatively new in India. Hospitals may not be prepared to handle such extensive legal affairs. This would explain why fewer Indian physicians reported that such an office existed, the variety of responses on which the office was, and why fewer Indian physicians feel the need to report a medical error.

While the small convenience samples and sensitive issues addressed prevent generalisation of these conclusions, these findings suggest that both cultural differences and similarities exist and they are not necessarily what we would expect them to be.

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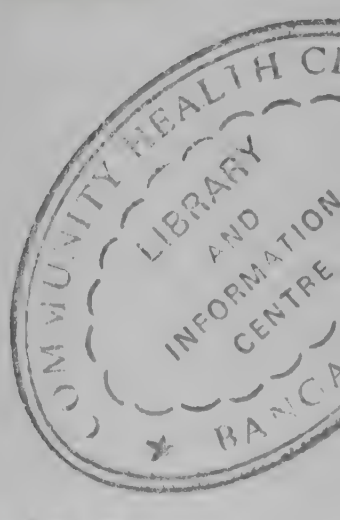
Medical technology and social justice

No longer are advancements in science and technology viewed as unqualified benefits. Technology is inextricably linked with money and markets, and we must examine the social dimensions of technology as it is applied in medicine. In general, in market-driven economies such as India, the poor have benefited very little from high-tech medicine. It has also become an instrument of perpetuating social biases and economic inequities. In this section we present discussions of two such technologies – organ transplantation and sex selection – and the differing views as they have been reflected in the journal. The debates continue but it is evident that high-tech medicine has changed our understanding of basic concepts of life and death, benefit and harm. Technology presents possibilities for both use and misuse, taking ethics into a completely new arena. These essays look at the dilemmas faced by individual practitioners as well as the larger social concerns about the role of medical technology in society and the profession's responsibility to promote the public good.




SURGEON TRANSPLANTS A PIGS HEART INTO A HUMAN..
Mohpa

Ethical problems in renal transplantation: a personal view

M K Mani

A nephrologist writes on different aspects of renal transplantation based on his own experience. Starting with the specific problems of making decisions about transplantation and seeking informed consent from donors, he discusses the question of giving patients sufficient information to enable them to make an independent choice. He reflects on the larger question of the justice of a technology which creates a deeply exploitative relationship between rich buyers of kidneys and poor 'sellers' of the organs. He speaks specifically of the role of the practitioner, who acts as a broker in this deal.

The golden age of medicine for the individual medical man was the last century. There were few effective drugs available and all the doctor could do was to "cure sometimes, to relieve often, to comfort always." No one expected a doctor to prolong life, and the profession had little responsibility and every opportunity to be noble. Medicine was an art and hardly a science.

The last fifty years have been a golden age of a different sort. There has been a logarithmic increase in our knowledge of diseases and in our therapeutic armamentarium. It has not been an unmixed blessing.

Primum non nocere (First, do no harm)

The power to do good always carries with it the capacity to injure. Effective medicines have horrendous side effects and we often do active harm to our patients in our efforts to help them. Many of us face tortuous decisions day after day. Should I put a patient on cyclophosphamide for glomerulonephritis? Will he suffer some serious infection and die as a result? If I withhold the drug, will he die of renal failure that could have been prevented? Should a surgeon take a patient for an operation that carries risk to life? Is

he sure the patient will die of the disease and cannot recover with conservative treatment?

All these dilemmas pale into insignificance beside the predicament in which transplantation places us. The worst of all is renal transplantation, because the kidney, being a paired organ of which we need only one for life, can so easily be removed from a living person. This leads us to perpetrate the ultimate in horrors, a hazardous operation on a healthy person, and grievous hurt by the 'healing profession'. A few of us have been catalysts in the development of renal transplantation in this country. I do not know whether to pride myself on this, or to hang my head in shame.

The patient with chronic renal failure: options and costs

Let me begin by stating a few basic facts. The patient with chronic renal failure has three options, each with subdivisions. First, he can receive a renal transplant, which could be from a relation, a live unrelated donor, or a cadaver.

The main difference between these is that he has a good chance of success with a related donor even if he uses azathioprine, which would cost him approximately Rs 5,000 a year, but the unrelated kidney from a live or cadaver source will be successfully grafted only if he uses cyclosporine for a period, and this drug costs Rs one lakh a year. Many doctors claim to have successfully weaned their patients off the drug after some time, usually a year, but that still means an additional cost of Rs one lakh.

What must be stressed is that cyclosporine has only made a difference to short term survival of the graft. Long-term survival depends on the degree of matching between the donor and the recipient. A full-match sibling-graft has a half-life of 25 years. Any other half-matched relation has a half-life of 12 years. The unmatched cadaver or unrelated live donor graft has a half-life of 6.5 years, even if cyclosporine is the immunosuppressive used.

Second, the patient can stay on dialysis. This could be haemodialysis, which he could take in hospital for a cost of Rs 1.2 lakh a year, or at home for a cost of Rs 2.5 lakh to buy a machine, and then Rs 50,000 a year for its running. He could go on Continuous Ambulatory Peritoneal Dialysis for a cost of Rs 1.3 lakh a year and could carry out this treatment at home.

Both these modalities are now available in some centres in India, and the long-term survival is good, with a reasonable quality of life.

Third, the patient could quietly go home and die. From the point of view of the family, this is often the best option. Whatever the treatment, it is expensive, and usually the family is poorer for it. Treatment often requires the sale of property or the need to take large loans, and only a few people in our country earn enough to repay them and leave the family richer than it was before the illness struck them.

The only option at least a few Indians can manage on their own income is a related donor transplant with azathioprine. I have seen gold chains disappearing from the necks of ladies and being replaced by a yellow cord to hold the mangalsutra, and silks yielding to faded cottons and I have been left with the guilty feeling of having pushed a family into poverty. Ethical dilemma No.1.

The kidney donor

Let us now turn our attention to the donor. We always reassure him or her that the donation of an organ is quite safe and that life can be carried on safely with one kidney. True, but the kidney is removed by a major operation and all major surgery carries a definite though small risk to life, perhaps 1 in 1,000.

The newspapers carried reports of two donor deaths in Madras during the last few years and there might have been others that did not come to the attention of the public. Hospitals and transplanting doctors do not publicise their failures, especially donor deaths. If the donor of a kidney gets a renal disease himself later in life, he has a smaller renal reserve and will go into renal failure much faster than if he had both kidneys available. It is mandatory that we should stress the risks when we talk to the prospective donor, and that our conversation should be confidential and that he should be given the option of telling the doctor that he does not wish to donate the organ. The doctor should then invent a medical reason for not accepting the donation, so that the family should not be aware of the reluctance of the donor designate. This is ethical dilemma No.2.

I have always regarded a medical certificate as a sacred document and think poorly of doctors who attest to falsehoods and yet I have

to tell a lie to preserve harmony in the family. I have done this on at least three occasions. Once, the prospective donor told me, three days before the operation, that she had changed her mind. I hurriedly ordered a test and in collusion with the biochemist, had it reported marginally abnormal and therefore declared the donor medically unfit. I had to listen to a well-justified diatribe from the husband of the patient for my carelessness in not having done this essential test earlier and for having put the family to great inconvenience and costly delay.

The unrelated live donor: adequate compensation for risk?

The greatest problem lies with the unrelated live donor. The idea of someone having to sell a part of his body for any purpose is repugnant to us and our reflex reaction is to abhor it. Let us think it over rationally.

There are three parties involved. The donor who sells his kidney, the patient with renal failure who buys it and the medical man who serves as a broker, a commission agent who effects the transfer of ownership. In view of the multitude of active programmes all over the country, it is clear that all three parties are happy about the present situation and are willing and even keen on perpetuating the present practice. What right has any one else to intervene? The patient is a man or woman on the verge of death, clinging desperately to a hope that this operation will bring him or her back to a full life and not necessarily one treacherously exploiting the working classes. The donor is a poor man with the laudable objective of earning some money by the sale of his only asset, perhaps to educate his son, perhaps to get his daughter or his sister married, perhaps to pay for an operation on his wife. He or she is not necessarily a drug addict seeking the wherewithal for the next fix. The doctor is a noble soul, desperately trying to save his patients at great difficulty to himself and not necessarily one who is interested only in the money he can extract from the recipient and in retaining for himself the lion's share of the proceeds. Unless otherwise proved, we have no right to view any of the three as anything other than what they claim to be.

But nagging doubts continue to assail me. Let us begin with the patient. Has he or she been informed that the half life of the kidney

will be only 6.5 years, in other words, that he or she has only a 50 per cent chance of the kidney lasting more than six years? Has the doctor mentioned the fact that there is no certain way of establishing whether the donor has some viral disease which could cost the life of the recipient, that the tests now available are not 100 per cent reliable and that the person intent on selling an organ is not going to release information which would preclude the sale of the organ? Has the patient been told that there are excellent alternatives with fewer such risks, such as the different forms of long-term dialysis?

The biggest source of doubt, of course, is the donor. Would he be as willing to give his kidney if he knew that donors can die as a direct result of the operation? The chances of dying are small, but not negligible. What about the risk of his developing renal failure himself, due to some renal disease developing later? I have seen renal failure years after nephrectomy in three of my donors. Two went into the end stage and needed renal replacement. My donors are all related and the family rallied round and someone else offered each of them a kidney. What is the chance of this happening with an unrelated donor?

We are, of course, exploiting poverty all the time. I do not climb the coconut palms in my garden, but pay someone else to pick the nuts that I enjoy. We pay people to entertain us at the risk of their lives, trapeze artistes and lion tamers, for instance. There is a difference. They are living by their skills; the renal donor is at the mercy of the surgeon. Is he being paid a realistic sum for his sacrifice? Who decides that Rs 5,000 or Rs 10,000 or even Rs 50,000 is adequate compensation for an irreplaceable asset, for life itself? This is a buyer's market, where the buyers are all rich and the sellers are all making distress sales.

Noble medical profession?

The greatest mistake mankind ever made was in describing the medical profession as noble. We now claim nobility in all our actions and doctors doing unrelated donor transplants say they have to do it because they are committed to their patients and have to do it to save their lives, however distasteful the means.

The argument is specious. We do transplants only for some fraction of the people with renal failure in the country, maybe two or three

per cent. Have we no duty to the rest, who are too poor to come to us in the first place? Have we no duty to the donor? We ease our conscience by saying that the donor is well rewarded by being given the wherewithal to pay his debts or to buy a hut or a bicycle. If we were really interested in the donor, would we not organise an international auction for his kidney? Surely the rich Arabs and Chinese who buy our kidneys could pay lakhs for them instead of this pittance. Should not the donor receive more for the transplant than the medical man who is merely a broker in the deal? If a broker helps me to buy or sell a car, he receives only a fraction of the price, not the lion's share.

Kidneys from cadavers

We are told that the country is not ready for cadaver transplantation because it is costly and requires a complicated technological set-up. This is nonsense, an argument raised by vested interests. The set-up in the West today is elaborate and well beyond our means, but so is every aspect of medicine. Even a live related donor transplant in the West is done with a degree of sophistication beyond us, at a cost at least twenty times as much as here. I was involved in a cadaver transplant programme in Australia when transplantation was in its infancy all over the world. The concept of brain death did not exist. We waited for a person to die in the old fashioned way, by entire and continuous cessation of respiration and circulation, and then took the kidneys within an hour of death and got a reasonable 60 per cent one-year graft survival, using only azathioprine. There are units all over the world that are using such donors today, people who die outside hospitals or before they get on respirators and their results are only marginally worse than those with heart-beating donors. In 1968, Australia did not have sophisticated computers and a trans-national movement of organs. All kidneys harvested were used within the city, within eight hours and I see no difficulty in establishing the same system in Madras. The cost would be rather less than that of the unrelated live donor, as we can do without a number of investigations needed to safeguard the life of the donor. We need to have the backing of the public for this, with wholehearted willingness to donate organs after death. The effort that the unrelated donor lobby is using to prevent cadaver

legislation would better be utilised to persuade the public to accept the concept of donating all organs after death.

We have an Act to regulate transplantation now. It is a far-sighted piece of legislation, bringing in the concept of brain death, making it possible for us to decide during life that we wish to donate organs after death, firmly prohibiting commerce in transplantation and introducing some regulation of the whole transplant industry. Of course it has flaws and many people on both sides of the question have spent much time pointing out where the law would be misused. It is up to us to put it to good use and the effort we have spent arguing about it would have been better utilised had we got on with the job of making it work.

The gift of life

Unrelated live donor transplantation should be banned because there is an alternative for the patient with terminal renal failure in the form of dialysis or cadaver transplantation, because the donor will always be a poor and ignorant man who will be exploited by the doctor, the patient and the broker and because we will never have cadaver transplantation unless the easy way of buying a kidney is closed to the rich and influential. They will then turn their efforts to establishing cadaver donation in the country. A time will come when it will seem quite natural for every one of us to give life even as we leave the world, with gifts of kidneys, livers, hearts, lungs and to give sight to the blind. Our organs will live on after us.

This is truly the path to immortality.

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The ethics of organ selling: a libertarian perspective

Harold Kyriazi

In a radically different view, this writer opposes a state ban on trade in organs as an infringement of personal freedom. He argues that a free trade in organs would allow the poor to benefit from selling their organs. He also believes that it would be more effective to move from living donor-based transplants to cadaver transplants through a public campaign. These dilemmas are discussed in the Indian context.

First principles

As a libertarian, I believe that people own themselves. Any alternative would involve some form of slavery. And as owners of themselves, individuals have the right to sell their organs, give them away, and even to allow themselves to be "harvested" of their organs in a productive form of suicide, for whatever reason they choose. (Of course, surgeons and hospitals would be free to denounce, and to refuse to perform, such macabre procedures, and medical societies would be free to expel members who assist in such suicides.) Having said that, I also wish to emphasise that I share the concerns expressed by bioethicist Stephen G Post, of the Case Western Reserve University School of Medicine's Center for Biomedical Ethics:

"...in India, where a huge black market in nonvital body parts provide kidneys for the wealthy, it is the poor who sell. Is this truly freedom, as the libertarian proclaims? Or is it a forced choice made in destitution and contrary to the seller's true human nature? I see such a market as the most demeaning form of human oppression, as unworthy of any valid human freedom..."(1)

But one could make the same argument for coal miners and others with dangerous jobs who risk life and limb to support their families. Certainly such people are better off having these additional choices. But while it is a pernicious paternalism that would seek to deny the

poor these choices, it is also a sterile libertarianism that would stop the inquiry here, hailing the enlarged freedom of the destitute, and looking no further.

Margaret Radin, professor at the University of Stanford Law School, reached a similar conclusion:

"If people are so desperate for money that they are trying to sell things we think cannot be separated from them without significant injury to personhood, we do not cure the desperation by banning sales.... Perhaps the desperation is the social problem we should be looking at, rather than the market ban. Perhaps worse injury to personhood is suffered from the desperation that caused the attempt to sell a kidney or cornea than would be suffered from actually selling it. The would-be sellers apparently think so. Then justice is not served by a ban on "desperate exchanges."... We must rethink the larger social context in which this dilemma is embedded. We must think about wealth and power distribution."(2)

And so we are led to consider the larger societal question of basic economic justice. But before discussing the world as it should be, I wish to make a few comments about the ethics of the world of organ transplantation as it is.

Comparing the Indian and US situations

Both India (three of the key states in 1994, and others subsequently) and the US (nationally in 1984) have banned monetary compensation for human organs. The ban has been effective in the US, while it is routinely circumvented in India. But which system is the more ethical? In India, at least, those upper class Indians and wealthy foreigners who need organs are getting them, while some of the poor are afforded more financial opportunity than they would otherwise have. In the US, however, over 5, 800 people - rich and poor alike - die every year while waiting for donor organs that never arrive. And with most such deaths are associated years of waiting, years of debilitating sickness, and years of mental anguish not only for the ill, but for their families and friends. Against this horrendous backdrop, is a ban on market activity ethically sound? Another professor of law, Lloyd R Cohen, of the George Mason University School of Law, thought not: "People are dying while the organs that could restore them to life, and that a market (3)

would provide, are being fed to worms. Were more to suffer and die for want of organs that a market would provide, the high minded pieties that support the prohibition would be revealed for the vacuous moral posturings that they are."(4)

Finally, on this issue, Professor Radin insightfully notes that the US position-that altruism shall be the only permitted motivation for organ donation-may simply be a convenient way of shutting its eyes to the desperation of its own poor. "To preserve organ donation as an opportunity for altruism is also one way of keeping from our view the desperation of poor people."(2)

Let us now proceed to the heart of the matter – poverty and economic justice.

Economic justice

The essence of economic injustice, as it is currently instituted – essentially worldwide – is no longer chattel slavery, as it was in the 19th century and before, but wage slavery. And wage slavery is made possible by land policies that allow a small portion of mankind to monopolise the land on which and from which all must live.

Said 19th century American economic and social philosopher Henry George, "...the 'iron law of wages'...which determines wages to the minimum on which labourers will consent to live and reproduce...is manifestly an inevitable result of making the land from which all must live the exclusive property of some. The lord of the soil is necessarily lord of the men who live upon it. They are as truly and as fully his slaves as though his ownership in their flesh were acknowledged." (5)

I cannot here go into detail about economic justice, but I refer those interested to my recently published book on the subject (6). The short answer, however, is that those who 'own' land and natural resources should pay to the community a yearly rental fee, based on the market value of their holdings (irrespective of buildings or other improvements). Such a fund will guarantee landless citizens at least a minimal income, and also pay for the valid expenses of government. More importantly, the community's act of charging market prices for land and natural resources will help ensure that the latter are put to their highest and best use, generating more jobs and wealth for all. Additionally, no taxation should exist on

productive human activity (such as working, via wage and income taxes; buying, via sales or value added taxes; saving and investing, via income and capital gains taxes; giving, via gift and inheritance taxes, etc.), as that punishes – and hence lessens – good behaviour, while robbing people of the fruits of their labour. From what I understand of recent Indian history, efforts at land reform in the various states have been economically counterproductive, aimed at forcibly subdividing the land itself (7) rather than merely its economic rent. My impression of the Indian economy in general is that central planning and control have effectively stymied individual initiative. But all that is necessary for people to thrive economically is for them to have free and equal access to the earth (or its equivalent in rent) and the rights to free action and free association (i.e. to engage in entrepreneurial and free market activity), with the only proviso being that they do not violate the equal rights of others.

The US has, of course, long championed the latter freedoms, but has ignored the injustice inherent in its monopolistic system of land tenure. It was able to escape most of the harmful consequences of the latter for much of its history by virtue of its frontier, which provided a safety valve for oppressed labourers, who could escape wage slavery by homesteading frontier land, thus becoming their own masters. That avenue of escape was gradually eliminated, and the US then took the indirect route of wealth redistribution (via income, estate, and other forms of taxation) to attempt to redress the situation, rather than eliminating the injustice at its root.

As Winston Churchill said, "Land monopoly is not the only monopoly that exists, but it is by far the greatest of monopolies. It is a perpetual monopoly, and it is the mother of all other forms of monopoly" (8). Thus, while many forms of monopoly now exist, and many people make money in partly unfair ways in many fields other than real estate and natural resource utilisation, these other forms would not be possible without the primary monopoly of land and natural resources. The US and most other countries have thus allowed the privileged to retain their immoral means of subjugating their fellow men. (Not that I believe the privileged are, in general, aware of the partly immoral nature of their means of attaining wealth. If they could perceive the basis of the injustice, so also

would most others.) But perhaps the day is coming when the masses will understand the true nature of their plight, and will take proper remedial action.

A proper ethical focus

A primary ethical focus throughout the world must be the establishment of true economic justice, along the lines discussed above. Only in that way will the question of the exploitation of the poor be properly addressed and satisfactorily answered – by the elimination of poverty.

Additionally, most of the world needs to adopt something like the *de facto* (but not *de jure*) system now in place in India, by permitting monetary compensation for organs. Said Henry Hansmann, of Yale Law School: "...this prohibition may be overly broad... It appears possible to design suitably regulated market-type approaches to the acquisition and allocation of cadaveric organs (and perhaps of organs from living donors as well) that will be neither unduly offensive to ethical sensibilities nor easily abused..." (9)

For most of the world, cadaver tissues and organs should be adequate to meet demand. This seems a reasonable assumption, given that Belgium – which has a policy of 'presumed consent', in which people are presumed to be willing organ donors unless they have indicated otherwise – has such a surplus that it is able to supply many foreigners with needed organs (10). And data from the US on accidental deaths, where the death itself occurs in a hospital setting, suggest a potential surfeit of transplantable organs (11). The laws against monetary compensation thus need to be repealed, allowing organ procurement organisations the freedom to use whatever financial incentives are required to bring the supply up to meet demand. (From an ethical standpoint, it would be wrong to use live donors when cadaver organs are available, assuming that cadaver organs are equally as effective and safe as those from the living. If this is not the case, i.e. if cadaver organs stand a greater chance of failing or infecting their recipients than those from living donors, it would require careful consideration and balancing of the risks to donor and recipient to decide the proper course of action. Nevertheless, it is the individuals involved, and not legislators and bureaucrats, who should make such decisions.)

For most of the world, then, the question of the ethics of living donation will be a peripheral concern, arising only in cases of extreme time urgency, when one simply cannot wait for a cadaver with the proper tissue match to become available. In those cases, live donation, in which the pool of potential donors is much larger, will continue to be the only viable option. For India, however, for a variety of reasons, any large-scale use of cadaver organs is not currently feasible. Thus, for India, live donation will continue into the foreseeable future.

Summary

Given the above considerations, were I a transplant surgeon in India, I would have five relevant ethical concerns: 1. Economic justice: support the establishment of genuine economic justice. 2. Cadaveric vs. living donors: support a transition from a system emphasising living donors to one relying mostly on cadaver organs from those who have suffered brain death. 3. Fair compensation: try to ensure that donors are paid as much as possible (since the current market contains some degree of exploitation, due to the entrenched economic injustice). In practice, this would entail dealing only with organ brokers who treat donors fairly. 4. Do no harm: over and above the usual concerns expressed in the Hippocratic Oath, take all reasonable steps to ensure that patients have adequate follow-up care and legal options for redress of grievances. 5. Legalise organ selling: because the above-mentioned legal options are unlikely to be feasible under a black market system (lawbreakers rarely wish to attract legal attention to their own 'criminal' behaviour), one must seek to remove the laws banning organ selling. Their existence in an atmosphere in which black market activity nevertheless thrives not only places those involved outside the protection of the law, but engenders disrespect for law and law enforcement in general, to the detriment of society. More importantly from an immediate standpoint, removing the ban will free the operations from the clutches of organised crime, and make transplants less expensive for recipients, less exploitative of poor donors, and less dangerous for all involved (12).

For anyone seeking further libertarian perspectives on this issue, especially as it relates to US policy, a good source is my website, at www.organselling.com

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The case against kidney sales

George Thomas

This article was written in response to the argument supporting a regulated organ trade. The author views the organ trade from the perspective of the seller, whose problem of poverty is not necessarily resolved by the sale of an organ. It describes organ selling as a new form of slavery. The essay stresses the importance of ethical means as opposed to a utilitarian concern for ends. This essay and the preceding one by Harold Kyriazi were published as part of a collection on ethical issues in organ transplant.

> "The philosophers have only interpreted the world in various ways; the point is to change it."
>
> – Karl Marx: *Theses on Feuerbach*

I am one of those who, according to Radcliffe-Richards et al oppose the practice of buying kidneys from live vendors from a feeling of "outrage and disgust" (1). These feelings are by no means irrational. They are based on a bedrock of moral principle: that no human being should exploit another. The opponents and proponents of the trade in human organs are divided by this (perhaps unbridgeable) chasm. The one side is wedded to the belief that not only are all human beings born free, they should also stay free. The other is not so sure. The evolution of human civilisation has witnessed several periods of gross exploitation of human beings. Slavery, the extermination of six million Jews, and today the transfer of body parts from one living human being to another for a financial consideration, are part of a continuum of values which sees some human beings as less valuable than others. It is this value system that those of us who oppose the sale of kidneys seek to change. All arguments in favour of the trade are attempts to clothe, in the garb of reason, the concept that it is all right to remove a body part from a poor person and put it into a rich one. But even these arguments will not bear scrutiny and I will deal with them below. First, the argument that the prohibition of organ sales worsens the position

of the poor because it removes an option in their already deprived lives: Here the authors (1) of the paper have cleverly stated the most potent contrary argument themselves: the solution is the removal of poverty. They, however, appear to consider this a distant possibility, and in the meantime advocate the selling of kidneys as one option available to the poor to better their circumstances. It would have been useful if the authors had adduced material to show how and how long this so-called option works. In the absence of any sustained means of livelihood, it is quite probable that the money obtained by the sale of one organ will soon be gone. What shall the seller do next? Sell another organ? An eye? A lung? And when all the paired organs are gone?

Let us accept that the risk involved in nephrectomy is not high. But is it not a fundamental tenet of medicine that the risk must be in the medical interest of the patient? What medical advantage does the donor obtain? Undoubtedly the risk is the same for those who sell and those living donors who do not sell but donate out of regard for the recipient. Radcliffe-Richards et al move from this fact to the inference that therefore there should be no difference between the two groups with surprising facility. What matters here is motive: the implicit coercion in the case of the poor who sell out of financial compulsion. Radcliffe-Richards' equating of the motives of the better-off, and comparing the risks of nephrectomy with the risks of dangerous sports, can only be described as callous. No one prevents them from campaigning against these sports if they are so moved, but for us activists in the Third World there are more pressing matters than looking after the well-being of the jet-set. A profile of the sellers would be revealing. It will come as no surprise that they all belong to the third world. And it will also come as no surprise that besides the wealthy in the third world, the potential buyers will be from the rich, white, First World and from the petroleum-driven *nouveau riche*. No wonder a veritable industry of philosophers has risen in these countries to justify this horrible practice. And in the honourable tradition of colonialism there will always be locals ready to aid and abet the conquerors. He who pays the piper calls the tune.

Radcliffe-Richards et al (1) seem fixated on the belief that legalising and controlling the trade in human organs will protect the exploited. The situation in other fields shows that this is naïve indeed. In Hamburg, legal commercial sex workers throng the glittering Reeperbahn, while in the sad, sordid, shadowy bylanes the illegal commercial sex workers have no shortage of clients. This, in a country where social conditions ensure much closer adherence to the rule of law than is the case in most developing countries, which are the main source of people willing to sell their organs. In India, child labour is a reality. Poverty is the main reason for its existence. The efforts of numerous groups have succeeded in making it illegal. Have they removed an 'option' for the poor? After all, the poor consciously send these children to work. Would it be a good idea to legalise the practice and control it on the theoretical basis that it would improve the lot of these unfortunate children? There are many reasons why such trades will always be open to exploitation. The most potent one is that the victims are poor and voiceless while the beneficiaries are generally rich and powerful.

The argument that organ selling is acceptable because some services are available to the rich, that are not available to the poor, is extremely strange. Do the authors believe that the presence of undesirable practices justifies adding a few more? What will the limit be? Who will decide how many more are to be allowed? No prizes for getting it right. The answer is: the rich and powerful permit whatever is in their interest. They can always hire a motley crew of philosophers and technicians to justify it and make it possible. Why is altruism necessary in organ donation? It is because it will ensure the absence of exploitation. It is nobody's case that unless some useful action is altruistic it is better to forbid it altogether. Altruism removes the profit-making element. It will help ensure that organ transplantation is done in the best possible way and thereby achieve the best possible medical result. It will also ensure that no vital organ is removed from a living person. On the other hand, a trade in kidneys definitely puts one on the slippery slope to selling vital organs as documented elsewhere (2). Here, the authors utilise the familiar stratagem of positing and demolishing

imaginary weak arguments against their stated position, while ignoring the real and powerful argument.

The authors end with an emotional appeal that feelings of repugnance among the rich and healthy cannot justify removing the only hope of the destitute and dying. A powerful statement indeed, but on whose behalf? Is the only hope for the destitute the sale of body parts? Is this modern form of slavery where one sells oneself piecemeal, as opposed to the old form where the entire person was sold, the only hope for the poor of the 21st century? Or are the authors unaware that there is enough for all if only the rich were not so greedy (3)? Although they themselves state that the real solution to selling is the removal of poverty, they quickly move on to the reasons why selling is acceptable today. The entire tenor of their article suggests that they are not interested in this, the real option. Perhaps it is difficult to push this idea in the West where the dominant paradigm is to maintain the current wasteful level of living, never mind that it is at the direct cost of millions of other human beings living elsewhere. How much easier to go for the soft option of buying kidneys from the poor and making this appear as good for both the seller and the buyer. As for the dying, it is clear that the authors are not concerned about the poor who are dying, as they cannot afford transplantation and all the costs after transplantation. As for those who can afford transplantation, is the transfer of a kidney from a poor person really the best option? People who have undergone dialysis do not seem to think it such an unpleasant experience as the authors would have us believe (4). Let us not forget also that transplantation is not the end of the story but that the patient has to be on lifelong immunosuppression, which is quite an expensive proposition.

However, it is true that many who would be helped by transplantation are unable to get an organ. The real solutions lie in popularising cadaver transplantation, increasing the donation rate from the brain-dead, and working on technology to make dialysis cheaper and more tolerable. Radcliffe-Richards et al state that a vendor will never be a potential donor even after death. This is by no means certain. Methods can be found to increase donation rates from the brain-dead and from cadavers. One has only to see the amazing success of the Sri Lankan eye donation programme to

understand what can be achieved. This is the difficult option but the only sustainable one. Nothing can justify using one human being as an organ farm for another.

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The ethics of sex selection

Ruth Macklin

Women's groups and health groups in India led a campaign forcing the government to ban sex selection. They did so because they believed it was important to use modern institutions like the democratic state and the legal system in the fight for women's rights. In this context, it is interesting to read an American ethicist's analysis of sex selection from a sociological perspective. The writer admits that sex selection may have harmful consequences in the long run but suggests that it also serves the immediate purpose of preventing the abuse of unwanted girl children. She argues for social reform instead of a ban on the practice. Written before the publication of 2001 census data established the impact of sex selection on the sex ratio, the article focuses on gender discrimination, rather than the misuse of technology.

The thought of women having abortions in order to choose the sex of their future children fills many with revulsion. To think clearly about this issue, it is necessary to separate arguments about the ethics of sex determination (SD) from those pertaining to abortion. People who find abortion ethically problematic will want to see its incidence reduced. We must contemplate SD carried out by pre-conceptional means rather than abortion following prenatal diagnosis as it is only a matter of time before techniques of sperm separation are perfected.

The premise of this article is that whilst SD is not a desirable practice, prohibiting it by law is likely to do more harm than good. This conclusion is clearly consequentialist – the only form of ethical argument that is plausible in this context. It is hard to provide persuasive reasons why SD is intrinsically unethical. No rights are violated when SD is allowed by law. Legal prohibition of SD will infringe upon the reproductive rights of women.

The consequences of legally permitting or prohibiting SD are bound to vary from one society to another. This analysis is limited to India and China, where SD is widespread and consequences are

more palpable than in North America. In these two countries, the methods currently used are post-conceptional and abortion is legal, without the religious and ethical abhorrence common among Christians, orthodox Jews and most Muslims. SD will probably never reach the proportion in the United States that it already has in these two Asian countries because the factors contributing to a strong preference for sons, so prevalent there, are absent here.

Preference for sons in India and China

In India, where abortion for the purpose of SD is widespread and shows no sign of waning, opponents refer to the practice as female foeticide or femicide (1, 2). A strong feminist movement in India condemns SD. The Forum Against Sex Determination and Sex Pre-Selection has engaged in political activism to promote a legal ban. In May 1988, largely as a result of the work of this group, legislation was passed in Maharashtra banning the use of medical techniques for prenatal diagnosis except in cases where the mother is at high risk of foetal abnormality (3). In 1994, the Indian Parliament passed a law that provides penalties of three years in prison and a fine of about $320 for those found guilty of administering or taking prenatal tests for the sole purpose of determining the sex of the foetus (4).

The social and cultural basis for preference for sons in India and China is long standing and deeply entrenched. Religious traditions and economic circumstances drive the preference for sons beyond that in most other countries. In both India and China, the family name is passed down through sons, who are also financially responsible for supporting their parents in old age. In India, a precept of the Hindu religion holds that a sonless father cannot achieve salvation and a significant Hindu funeral rite for fathers can only be performed by male children. An analogous tradition in China stems from ancient Confucian precepts that require a son to perform ancestral worship ceremonies.

The most striking determinant of son preference in India is probably the dowry system. According to one account, in the last two decades, fuelled by a consumer boom among the new Indian middle class, dowry has spread like an epidemic to communities that never practised it before. And its purpose has changed. No longer is it seen as a collection of wedding gifts to help a couple

start a new life; instead, it is a way for the groom's family to elevate its economic status (5).

These demands continue even after marriage. The consequences of failure to meet them can include ejection of the woman from the marriage and even murder by her husband's family

Economic factors evidently provide a major incentive for aborting female foetuses but the underlying cultural tradition of preference for a son remains a strong factor. A middle-class Indian woman, pregnant with her third child, underwent prenatal diagnosis for the purpose of sex selection. She already had two daughters and planned to abort if the foetus was another female. The family was reasonably well off and could afford another girl. They loved their daughters. The motivating factor was the social attitude. The woman told an interviewer: "Our society makes you feel so bad if you don't have a son... People say, 'How many children?' and I say, 'Two girls, ' and they say, 'Oh, too bad, no boy.' And I feel very bad." Interestingly, this Indian woman and her husband were Roman Catholics. She said, "Being a Catholic, it's the only sin I commit." But she added, "When this test is here and everybody is doing it, why shouldn't we have what we want?" (4)

In China, ancient Confucian ideology continues to influence the strong preference for a son, especially as the first-born child. In addition to the need for sons to maintain the family line and to perform crucial ancestral rituals, males are held to be smarter and stronger than females. Despite a law in modern China dictating that parental support is the duty of all children, males are still held responsible for the support of parents in old age. Women are not available for the care of their own elderly parents once they are married. Their productive and reproductive labours benefit their husbands' family (6).

Arguments opposing sex determination

The leading arguments in opposition to SD are: the practice devalues the female sex; it reinforces current attitudes and practices that discriminate against girl children and women; and it results in an imbalance in the sex ratio.

Each of these will be examined in turn.

Devaluing the female sex

Although it is no doubt true that a practice reinforcing the already existing preference for a son devalues the female sex, the question remains whether that is a sufficiently strong reason to institute legal prohibition. Who, if anyone, is harmed or wronged by the practice of SD? Surely not the female child who will not be born as a result of SD, since this is the child who does not know and will never exist. What about existing female children and women? Does SD harm or wrong them? This is where the debate begins and empirical evidence is needed to supply answers.

Some argue that women as a class are demeaned by a practice that seeks to avoid the birth of females. This avoids the critical question of whether girls and women are made worse off as a consequence of this practice than they are anyway or than they would be if SD were eliminated. The first possible consequence to consider is female infanticide.

A report published in June 1986 in *India Today* (5) estimated that 6,000 female babies had been poisoned to death during the preceding decade in the district surrounding the town of Madurai in Tamil Nadu. Methods of infanticide include feeding the baby the sticky white milk of a poisonous plant or cow's milk mixed with sleeping pills. One mother of a day-old baby who had been killed thus was reported as saying: "We felt very bad... But at the same time, suppose she had lived? It was better to save her from a lifetime of suffering."

The mother of another couple who had their second daughter killed said: "Abortion is costly... And you have to rest at home. So instead of spending money and losing income, we prefer to deliver the child and kill it."

Infanticide is viewed as an alternative to aborting female foetuses and, in the case of the second woman quoted, appeared to be the preferable alternative. It is not clear whether legal prohibition of SD produces an increase in the number of girl babies being killed after birth. Yet it is undeniable that from any ethical perspective other than an extreme right-to-life persuasion, aborting pre-viable foetuses is ethically preferable to killing full-term infants after birth.

A second, well-documented consequence for girl children in poor families is their being neglected in favour of their male siblings. Whether SD is legally allowed or legally prohibited, girl children are often denied adequate food and medical treatment in favour of their brothers. So if a family has one or more girl children and then uses SD to produce a male child, it is likely that the girls in that family will be harmed by inadequate food or medical attention. But the same consequences would result if a boy is born into the family without the assistance of SD. It is difficult to determine whether the practice of SD produces more harm to identifiable girl children than they would suffer in the absence of the practice. Nevertheless, it is clear that when SD is practised, the total number of girl children who can be harmed in this way is decreased.

Some of the consequences for women of legal prohibition in India have already become evident. Women for whom SD is less readily available as a result of its being outlawed are made worse off because:

(a) they have more children than they want or than is healthy for them until they have the desired number of sons; (b) some will go to private doctors who perform SD despite legal prohibition and the procedure will cost considerably more than when it was performed in public hospitals before the prohibition, and (c) those who do not bear sons risk having their husbands leave them without any means of support. Even affluent Indian families desire sons. Women in these families are threatened with divorce if they produce only female children. Following a divorce all property belongs to the husband, so these women may be left destitute.

The fact that the practice of SD contributes to devaluing the female sex is a good reason for judging it to be undesirable, but not a sufficient reason for legal prohibition. If women and their girl children in India and China are made worse off in other ways as a result of prohibiting SD than they would be if the practice is legally tolerated, an assessment of these consequences leads to the conclusion that SD should not be banned by law.

Reinforcing discriminatory attitudes

The second general argument opposing SD is that it reinforces current attitudes and practices that discriminate against girls and women. Evidence from Maharashtra, the Indian state that has had a legal prohibition of SD since 1988, suggests that prohibiting SD has not changed the preference for sons, nor has it done anything to enhance the position of women. Although it is surely desirable to increase respect for women and try to improve their status, there is little evidence that prohibition of SD does or will have those desired consequences. According to Madhu Kishwar, a fellow of the Centre for Study of Developing Societies in Delhi: "Statist measures such as banning the test and punishing those who go for it are likely to be both ineffective and counterproductive. Female foeticide is a symptom of devaluation of female lives, unless we are able to deal with all those social and economic factors that are going into the culture of son-preference and daughter-aversion, we cannot effectively combat the killing of unwanted female foetuses."(3)

Of course, it is not evident how these cultural attitudes can be changed. Professor Kusum, a scholar at the Indian Law Institute in New Delhi, contends that laws banning SD will not change the attitudes of the Indian people toward women. Instead, efforts must be made to try to change such attitudes by education rather than by law (7).

Thus, although it may well be true that SD reinforces current attitudes and practices that discriminate against girls and women, the converse does not appear to be true: prohibiting SD does not have the effect of eliminating attitudes and practices that discriminate against members of the female sex. Furthermore, legal prohibition in India does not seem to have succeeded in lowering the number of SD tests. The practice has simply been driven underground, with no way of monitoring the numbers or seeking to maintain quality control. After the ban, doctors who do the procedure have become unwilling to talk or provide information(3).

A physician in Bombay who formerly practised SD contends that enacting the law in Maharashtra has played into the hands of unethical people. Physicians who do amniocentesis sometimes do

it unscrupulously, telling women that the foetus is a girl when it is not. Financial motivation conjoined with legal prohibition has worsened the situation. The doctor in Bombay stated his own belief: "You can't violate the law of the land." He says that it was wrong to enact the law, but now that it is there, it must be respected (8).

In China, the return in the 1980s to family-based labour has led to the rise of patriarchal authority and discrimination against women. The immediate effect of this radically altered economic policy in a formerly centralised economy has been the desire or need for children, especially sons, to provide hands for work. Sons are thought to be better workers than daughters, and the demand for more children becomes a demand for sons (6). Conjoined with the state policy of a one-child family, the ultimate result has been a reinforcement of the traditional preference for sons. SD following prenatal diagnosis is therefore the consequence, not the cause, of discriminatory attitude and practices.

If the practice of SD reinforces current attitudes and practices that discriminate against girls and women, that is a good reason for judging it to be undesirable but not a sufficient reason for legal prohibition. It is hard to see how further restricting the options for women who already have limited choices in their lives can benefit them.

The danger of an imbalance in the sex ratio

Demographic figures from both countries reveal that a significant imbalance in the sex ratio has already occurred. In China, the 1990 census showed that of a total population of 1.2 billion, about 205 million Chinese over the age of 15 are single. Of those, there are nearly three men for every two women. Among people in their 30s, men outnumbered women by nearly 10 to 1 (9)

In India the ratio of men to women in the population, which has been widening throughout the century, has been tipping even more sharply toward men. Census counts show a trend: from 971 females for every 1,000 males in 1901, to 930 in 1971, and 929 in 1991 (10). In Haryana, a populous northern state that surrounds Delhi, the figure in 1991 dipped to 874 females for every 1,000 men, a disproportion said to be virtually unprecedented in similar counts around the world (4). Yet some have argued that the prenatal tests for SD cannot be viewed as

primarily responsible for the growing imbalance in the sex ratio. That ratio continued to decline sharply in the period between 1901 and 1971, when there were no tests. And between 1971 and 1991 the number dropped by only one point – from 930 in 1971 to 929 in 1991 (10).

As Jonathan Glover notes: "To refer to an imbalance between the sexes as a 'danger' may seem to beg a question. The traditional pattern is of a roughly equal number of men and women in any generation. Is it so clear that to depart from this would be disastrous?" (11) The answer, once again, can only lie in an assessment of the actual or probable consequences of an imbalance in the sex ratio. Some recent evidence has begun to emerge in China but at present such assessments are more speculative than based on empirical evidence.

Glover speculates that if two-thirds of a generation were male, a real problem could result. Men would feel that they are at a substantial disadvantage since many of them would be deprived of a partner. This, in turn, could result in a growth in prostitution and pressures towards polyandry (11). Kusum notes a similar fear about polyandry and adds to that the prospect of an increase in crimes like rape, incest and kidnapping. She also mentions the fear that "the reproductive burden on women will increase because the same burden of bringing forth progeny will then have to be shared by fewer women." (10)

Are there any possible positive consequences? One argument would be that an imbalanced sex ratio would ultimately benefit women. As women become scarcer, their value would increase. Women would then become valued in the way that rare jewels or one-of-a-kind art objects are revered. Glover rejects this argument on the grounds that it depends on an excessively economic view of relationships and of why people are valued...The argument is essentially that scarcity drives up the value of any commodity. But people are not commodities, and so the benefit to women from the imbalance is at least highly speculative (11).

The presumed negative and positive scenarios resulting from an imbalance in sex ratio are potential rather than actual consequences. The trouble with consequentialist arguments is

that they rely on projections or assumptions and they tend to stress those consequences that fit their authors' value predilections. Fortunately (or unfortunately), there is some reported experience from China.

One lonely 30-year-old man lamented, "Women are so hard to find now, and I just want one." (9) A government-sponsored computer dating service in Beijing reports that at least 70 per cent of the young people who come for the service are men. A social worker at the service observed that women have a good chance of finding a man who meets their standards, while men who ask for beautiful girls are told they must be realistic. Young men are reported to be dejected and pessimistic about their prospects. A 22-year-old engineering student despaired of ever finding a mate, while his friend speculated that "Without enough women, may be we will become monks." (9)

One rather cynical conclusion that might be drawn from these figures is that in these traditional, male-dominated societies, men are finally getting what they deserve. A more favourable outlook is one that envisages the benefits to women. Glover's rejection of people as commodities notwithstanding, a *New York Times* editorial cited market forces as a factor that has led to a new and higher value being placed on women. As a result of the current predominance of men, "suddenly young women are finding themselves valued in the society that once shunned them. They are being treated with new respect, and...have been rescued from disdain and oblivion by a highly impersonal and newly potent principle in Chinese life: market forces." (12) Guo Daofu, a senior economist for the State Statistical Bureau, speculated that the current shortage of women will play a positive role in improving the status of women: "I think this will lead to changes in society. Men will have to become more open-minded." (9) This prediction, though, is more speculative than it is based on any empirical evidence.

A darker picture is painted by Wang Wei, a professor of ethics at the People's University in Beijing, who noted a series of kidnappings of city women who were abducted by bounty hunters and delivered to rural farmers who were desperate for brides. "You could see more of that," Professor Wang said.

Conclusion

SD is an undesirable practice for the reasons stated by its opponents. Yet legal prohibition would restrict reproductive rights, hardly a desirable feature in countries like India and China that have both experienced serious violations of the rights of women by forced sterilisation and administration of state-imposed long-term contraception. Moreover, as already demonstrated in India, legal prohibition is likely to produce more harm than benefit to women and girl children in societies with strong preference for sons.

This conclusion must be tempered by the potential negative consequences of a severe imbalance in the sex ratio, as is already occurring in India and China. In both countries, social reforms rather than prohibition of SD are more likely to achieve desirable effects. Efforts should be made in all societies to increase respect for women and to enhance their status. An additional step in India is reform of the dowry system, which not only commodifies the marital arrangement but also oppresses the parents of girl children. In the end, it is social and cultural change not legal prohibition that can enhance the position of women in traditional societies.

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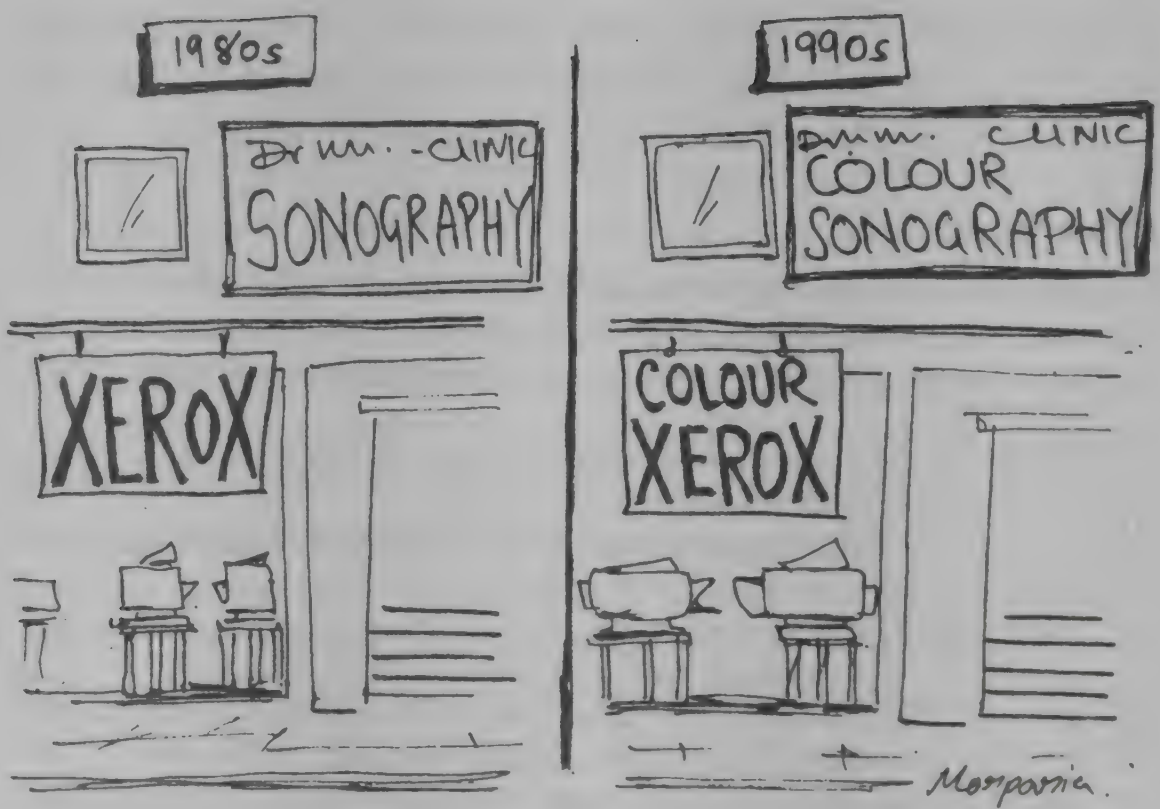

Sex selection: ethics in the context of development

Neha Madhiwalla

Data of the 2001 census show a clear relationship between the expansion of prenatal testing clinics and the skewing of the sex ratio. There is already a fairly widespread consensus that sex selection is unethical and unjust. This author writes against the background of the renewed campaign against sex selection following public interest litigation asking the government to implement its ban on sex determination as well as sex selection. The campaign is now clearly focused on the role of the medical profession in misusing medical technology. This article emphasises the need to develop a consensus within the profession to eliminate the practice, using self-regulation as well as legal provisions.

All too often we reduce 'son preference' to a crude caricature of starving, harassed and tortured girl children. However, the reality is much more complex. In the same society where sex selection is used as a new means to perpetuate an old bias, education levels are rapidly rising, floods of girls are going to school and college, there are more women working in offices and in factories, in panchayats and in Parliament.

It is actually not surprising that sex selection is highly co-related to development. After all, modernisation has made abortion available, accessible and morally acceptable to thousands of otherwise conventional families. And development itself brings new pressures. The cost of rearing children rises with the social imperative of educating them and providing health care. Some families may feel that such money and effort are better spent on boys rather than on girls; also girls are less needed in the new urban household, with small families and little need for unpaid labour.

It is in this context that sex selection must be understood. The movement towards more equal gender relations is, in a sense, inextricably embedded in the development process. However, the

resistance to it is stiff and takes new forms such as sex selection. Thus, on the one hand, middle-class families can allow their daughters to study after marriage, girls get sent to the best available schools, and women with 'girls only' families see older couples in the extended family managing without sons, buying houses for their married daughters, or sending them abroad. On the other hand, women still feel the pressure to have sons, and mothers of daughters find their children are not fawned upon as their sons may have been.

And this is the danger that sex selection poses. With one sweep, it threatens to reverse a process that has taken many decades to evolve. The power of technology can overwhelm the slow reflective process of change set in motion by millions of girls going to school and starting to work.

For a young urban woman such as myself, sex selection can never be an issue of mere academic interest. It is the lived experience of several friends, relatives and acquaintances. But I must address the question: how does one presume the availability of technology to make abortion and childbearing safe and accessible, and in the same breath ask for restrictions on its use? The Centre for Health and Allied Themes (CEHAT) is one of the co-petitioners in a Supreme Court writ petition calling for implementation of the Prenatal Diagnostic Techniques (Regulation and Prevention of Misuse) Act, 1994. And as a member of CEHAT's team, I feel the need to situate the campaign against sex selection in its proper context. Almost a decade of advocacy by CEHAT for more liberal abortion laws and services is obscured when we get clubbed with religious and quasi-religious political organisations holding diametrically opposing views on women and on sexual and reproductive rights.

The proponents of sex selection have various arguments. Sex selection is a personal choice, they say, and the state should not interfere in it. Intervening in matters of individual choice is a step towards greater state scrutiny and control. Rather than curbing the use of technology, we should spend our energies on educating the public and changing social norms. Some people also accuse us of imposing a western ideological perspective on people with a very

different value system. It is also argued that doctors should not be expected to play the role of moral police and reform their clients.

This perspective ignores the fact that the preference for sons is not personal, but completely socially determined. Second, the phenomenon of sex selection would never have existed without modern medical technology and is directly linked with the expansion of modern western medicine. In India, sex selection has risen along with the penetration of technology into semi-urban and rural areas. This is what distinguishes sex selection from other forms of neglect and discrimination that girls may face; it is not merely a manifestation of gender discrimination that households resort to. It is intimately connected to another phenomenon of development: the health care market. Doctors, as professionals, do not participate in infanticide or wife abuse. But they not only participate in sex selection, they benefit materially from it. And that explains the rapid proliferation of sex selection: it is good business.

Doctors and technicians know that sex determination for sex selection (without any medical reason) was never the intended use of diagnostic tools like amniocentesis and ultra-sound. However, because of the wide publicity that sex selection has received, many people are unaware of any other use for this technology. According to a recent study on abortion in villages of Pune district, while 75 per cent of the women (39 women) were aware that sonography could be used to determine sex, only four women knew that this technology was used to detect foetal anomalies (1).

Doctors represent society's elite, and what they say and do significantly affects public opinion. They lend legitimacy to the practice of sex selection by the very fact that they do not oppose it. Therefore, they will have to accept the challenge of reforming their own fraternity and influencing public opinion. No doubt, social reform has an important role to play in bringing about gender equality. What better group to begin with than one in which every member has at least five to seven years of college education and an income many times higher than the national average?

There is need for a law as well as a commitment from the profession to condemn and isolate those providers who engage in sex selection. The only real and lasting strategy to eliminate this practice is by building consensus within the profession. Only when

the option of sex selection ceases to exist will the coercion of women to abort female foetuses stop. As long as providers are willing to offer such services, women will remain vulnerable to such exploitation within their households.

Having said all this, ethical providers today may face dilemmas in individual situations.

Is sex-selection justified if the doctor is certain that the woman will come to harm if she bears a girl?

The doctor may indeed worry that a woman will be deserted or tortured if she bears a girl. However, the pressure to bear sons is only one aspect of the oppression that women suffer. In fact, as the family has no control over the doctor, the professional may be the only influential person who can argue against sex-selection without fear.

What if the woman herself requests it?

If the woman has been coerced by her family to ask for a sex-selective abortion, then by refusing one, the doctor is in fact acting in her interest. If she has really made an autonomous choice, it may be more useful for her to know that this act is illegal (many do not know) and that the doctor considers it unethical.

Is it all right if the couple already has one or more daughters?

How often do couples request an abortion because the foetus is male and they have too many sons? Only parents of girls have an urge to 'balance' the family, indicating that the whole process is discriminatory. Children lend variety to a family by their personalities, not by their sex. If family balancing was such an important issue for households, the sex ratio would never be so skewed. Many families voluntarily limit family size after they have had one or two sons, even when they do not have daughters. Significantly fewer families with only daughters do the same.

If you refuse to provide services, some untrained provider will.

Sex selection reduces even the qualified ethical provider to the same level as the unethical or unqualified provider: both are guilty of violating the law. In this way, professionals lose their moral

authority to demand the elimination of both unqualified as well as unethical providers.

Second, the influential urban middle class will not risk safety beyond a point and this will eliminate the largest and most lucrative market for sex selection.

How is sex-selective abortion different from the abortion of foetuses with serious genetic abnormalities?

When parents opt to abort a foetus with genetic abnormalities, they are concerned about the poor quality of life of the child that would have been born. A girl's disadvantages are not biological but social, and social change is more rapid and unpredictable than the improvement of prospects for the severely disabled.

This is not to claim that eugenic abortions are without ethical dilemmas.

Is the ban on sex-selective abortion not in conflict with the unrestricted right to abortion?

Through the anti sex selection campaign, right wing anti-abortion groups have suddenly discovered a love for the girl child. The unsaid message is that abortion itself is unethical and immoral.

Nonetheless, the opposition to abortion, and the ethical issues surrounding it, must be discussed by anyone serious about campaigning against sex selection. It is necessary to separate the two issues and yet see how they connect. The opposition to abortion is based on two arguments; the sanctity of life (including that of the foetus), and the fear that abortion will lead to promiscuity and the breakdown of the institution of the family. Often these two arguments enter each other's territory. One cannot challenge the personal views of those who would not opt for an abortion or conduct one themselves. We must respect a woman's freedom of choice to have a baby. We must also respect the choice of those professionals who would not like to participate in abortion. But the right to abortion, as a woman's right and without restriction, must exist. This is because women are often coerced to have sex, whether within or outside marriage. Second, contraception when available is not fool-proof and has its own risks. Third, women must bear the burden of the responsibility for contraception, of

childbearing itself, and of rearing children as well. Finally, the risks of childbearing are borne by women alone although women hardly ever have exclusive rights over the children born. Thus, access to abortion is a substitute for the rights denied to women otherwise by society (the right to have or not have sex, the right to ask a partner to use birth control or to look after the child).

Wherever safe abortion is available, women have used it judiciously. Freedom for women has strengthened families, not weakened them. What it has weakened is men's control over women – and in any case this ought not to be the basis of the institution of the modern family.

Thus the demand that women should have a right to their bodies and unconditional access to abortion is not in conflict with the claim that sex selection and sex-selective abortions are unethical. It is not the abortion that makes the act unethical, but the idea of sex selection. For one, the family that opts for the abortion of a female foetus is no different from the family that determines it is a male and therefore goes home happy. The ban on sex selection, like the right to abortion, is a proactive step; it gives a woman protection from coercion by the family and the right to respect, whether she bears a girl or a boy.

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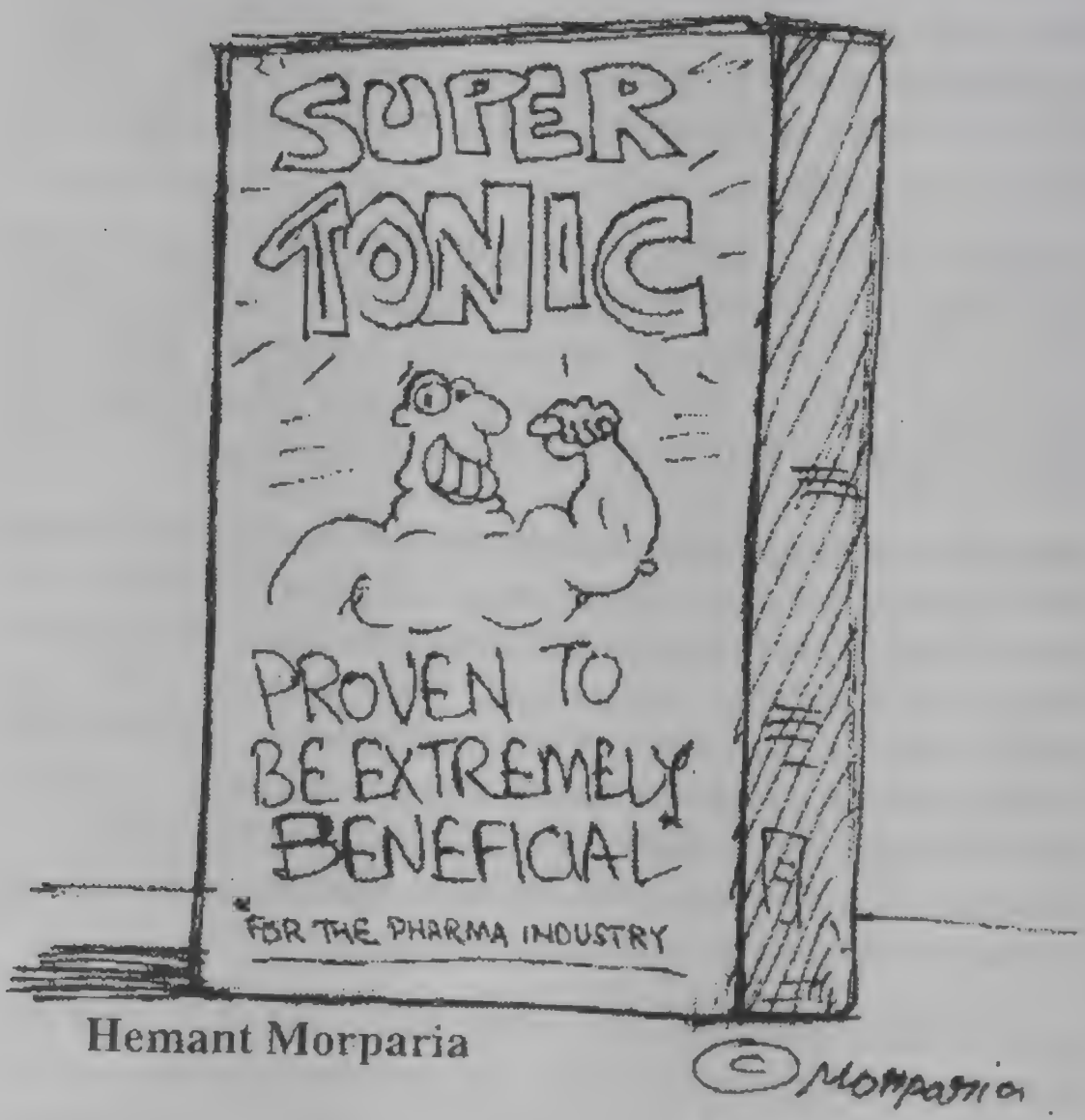
Research ethics

India is set to see a sharp increase in medical research. There has also been a rise in social science research in health. This raises a number of important ethical implications that merit serious discussion.

Research contains a number of inherent tensions: between the rights of the participant, the scientific interest of the researcher, the interests of commercial organisations, and the perceived social need. It often involves collecting personal information from people, submitting them to potentially risky situations.

Among the questions research poses are: is it acceptable to harm a few in the name of the larger good? And how do those who play the dual role of provider and researcher resolve the conflicts between their different obligations? How does the source of funding influence the choice of research question, the design of a study and the manner in which it is carried out? And how should research be conducted in settings where socio-economic inequities, resource constraints and other institutional limitations prevent the effective use of the knowledge gained?

Some of these problems are addressed by ensuring that all participants give their voluntary and informed consent, and by ensuring that research is conducted according to established guidelines, with ethical review and monitoring. And since the purpose of research is to add to the body of knowledge, fraud has implications for what is eventually practised. Fraud must be prevented by setting up institutional mechanisms. And research must be conducted in an environment of respect for colleagues and a fair recognition of their contributions.



Hemant Morparia

Research on hire

Amit Sengupta

Medical research has always been closely linked with business interests and these links are growing stronger over the years. Pharmaceutical companies have enlisted medical professionals in different settings, from general practitioners to consultants at large hospitals, in their research endeavours. Commercial medical research has proved lucrative for medical professionals and institutions. Universities view industry-funded clinical trials as a source of funds for their own research activities. However, such arrangements can compromise public interest. Moreover, 'collaborative' research is negotiated on terms unfavourable to the developing countries which serve as sites for research. The author describes the excesses of the industry and of physicians. He goes on to address the problems of out-sourcing research to developing countries with particular emphasis on India.

I recollect one of the first lectures in my first year of medical college where my venerable professor thundered: "... the first thing that a doctor should have is confidence. If you kill a patient, kill him with confidence." This is a classic expression of the necessity felt by the medical profession to maintain a veneer of confidence, even in the face of relative uncertainty.

In such a setting, medical technology is often used, not as a legitimate tool for diagnosis and treatment, but as a prop to hide inadequacies regarding knowledge about what constitutes the best course of action. In order to protect themselves from the anxieties that would otherwise accompany their relative ignorance, the profession seeks succour by immersing itself in the mindless pursuit of 'advanced' technology. The use of technology becomes an end in itself rather than a means to relieving human suffering. The last century has given us X-rays, ECGs, sonography, computerised scanning and much more. Yet, instead of clearing the prevailing chaos in medical practice, many of these tools have compounded the chaos. Not because it was inevitable, but because control over

these technologies has been the driving force behind the immensely profitable health care industry. Patients are over-investigated, over-diagnosed, over-treated and under-cared-for because the practice of medicine has to play second fiddle to large corporate interests.

Contract research

Medical research is often organised, paid for, commissioned or subsidised by the drug industry. The companies commissioning such research are only looking for conclusions that will enable them to market their product and reap profits. Nowhere is this more apparent than in the manner in which medical research is conducted in the 'seat' of the pharmaceutical industry, the United States.

An estimated 2 million Americans got hooked on to Redux (dexfenfluramine), a new anti-obesity drug marketed in the US by Wyeth-Ayerst, after it was approved by the US Food and Drug Administration (FDA) in April 1996. At the peak of its popularity, doctors were writing 85,000 new prescriptions a week. But a little more than a year after the drug's introduction, this craze collapsed, as patients began to exhibit symptoms of damage to their hearts and lungs. Fearing an epidemic, the FDA banned the drug in September 1997 (1). The manner in which 'scientific' evidence was created in favour of Redux is a shocking indictment of the system of medical research. In 1994, Wyeth had signed a $180,000 contract with a medical publishing company called Excerpta Medica that offered pharmaceutical companies an invaluable tool: readymade scientific articles placed in leading medical journals and carrying the signature of influential academic leaders. Excerpta laid out for Wyeth a schedule of nine articles, each with a carefully crafted message aimed at a targeted audience, from primary care physicians to cardiologists to nurse practitioners to pharmacists. The articles had a 'writer' and an 'author', but they weren't the same person. The writer was a freelancer who was paid $5,000 to actually write the articles. The 'author' was often a top university scientist who was paid $1, 500 to review the work and assign his or her name to it for publication.

The Redux story clearly focuses on the growing reliance of university scientists on corporate funding. Clinical research is now a multi-billion-dollar industry, with hundreds of testing and drug

companies working with thousands of private doctors. Patients have become commodities, bought and traded by testing companies and doctors. The number of private doctors in research in the US since 1990 has almost tripled, and top recruiters can earn as much as $500,000 to $1 million a year. Reports of fraud in drug trials are pouring in. Such abuses point to weaknesses in the new system that has developed in recent years for testing experimental drugs. No longer does the pharmaceutical industry rely on career researchers at academic medical centres, whose professional reputations are forged on the quality of their data. Rather, the industry has turned to thousands of private-practice doctors for whom testing drugs is a sideline for making money.

Research in developing countries

Medical research in the developing world suffers from the problems of underdevelopment, on which are superimposed the ills of a neo-colonial approach assumed by external research funding. In the developing world, research is poorly funded, monitored and prioritised. The situation is compounded by foreign domination in setting research priorities. While globally medical research is fuelled by corporate interests, the market for medical technology and pharmaceuticals in the developing world is very small. The size of the Indian pharmaceutical market, for example, is less than one-tenth of the market in the US or Japan. As a consequence, donor-driven research in developing countries (largely corporate-sponsored research) focuses on areas of interest in their home countries. Tropical medicine (itself a colonial construct) has a long history of descriptive studies that benefit researchers but have no direct implications for participants. For example, a bibliography of research up to 1977 in Papua New Guinea identifies 135 publications that describe Melanesian blood groups but only 25 concerned with treating malaria (2).

Different 'styles' of foreign donor-driven research are prevalent (3). There is 'postal research' where western researchers request colleagues in developing countries to courier to them biological samples. There is 'parachute research' where researchers travel to developing countries for short periods and take back biological samples. The most prevalent is the practice of maintaining 'annexed

sites' for field research, led and managed by expatriate staff. These annexed sites attract promising academics away from national institutions, and their research findings are infrequently translated into policy and practice. Research fellows in annexed sites may receive good training there but few return to national institutions. In a welcome development, India has recently forbidden annexed sites research and outsiders are now obliged to work through Indian institutions. However the long-term advantages of this move will, in all probability, be frittered away given the encouragement being provided to public sector R&D institutions to undertake contract research for corporate entities.

Drug companies have been known to perform research in developing countries that do not conform to the Declaration of Helsinki and could not be conducted in the developed world. Reasons quoted for conducting research in these countries, rather than developed countries, are lower costs, lower risk of litigation, less stringent ethical review, the availability of populations prepared to give unquestioning consent, anticipated under-reporting of side effects because of lower consumer awareness, the desire for personal advancement by participants, and the desire to create new markets for drugs. The commercial secrecy that surrounds early clinical research, and safety and dose ranging in phase 1 trials in paid normal volunteers (that is, poor volunteers), means that much preliminary research is unpublished, particularly when adverse effects are high and further development is abandoned (3).

Medical research in India

There is, however, no denying that India (as a consequence of its size and ability to pledge greater funds) is different from most developing countries. Real science and research is done mostly with public money and mostly in non-profit institutions. But such indigenous research funding is still too small and too badly organised to address local priorities. A report published in 1997 in *Current Science*, a journal of the Indian Academy of Sciences, suggested that most medical research in India is unrelated to the country's major health problems. The report, based on an analysis of research publications from India indexed in the Medline database, said that achievements in research have "little influence" on health

care delivery. It lamented that research seemed to be concentrated in the fields of tertiary health care and new biology (4).

There also exists a problem in defining local priorities. For long the two thrust areas for medical research in India have been vaccine research and research on contraceptive technologies (and, recently, reproductive health). Both priorities can be contested on the ground that they emanate from a view of public health that is technocentric – vaccines as 'quick-fix' remedies for communicable diseases and contraception to control population growth. Given the hype surrounding both these concerns, government-funded research in these areas has scant regard for standard ethical guidelines.

Unethical and dubious

The decades of the 1980s and 1990s have thrown up numerous instances of unethical and dubious research in the country. Research on long-acting hormonal contraceptives like Net-En, Depo Provera and Norplant have been conducted without observing ethical requirements like informed consent and the need to follow up participants.

A team headed by Dr G P Talwar at the National Institute of Immunology (NII) persisted for years with trials to develop a contraceptive vaccine despite criticisms that these trials were being run unethically. The vaccine passed through phase 2 clinical trials in the late 1980s. Only 80 per cent of the women who received the vaccine showed the adequate response necessary for contraception. More importantly, according to published reports on the trial, only 94 out of 162 women in the trial 'volunteered' for long-term follow-up. The Indian government did not give approval for phase 3 clinical trials of the vaccine but continued to fund the research on contraceptive vaccines. The trials were put into 'cold storage' only when Dr G P Talwar retired from the NII. In 1998 it was revealed that the Institute for Cytology and Preventive Oncology had left cervical dysplasia (a pre-cancerous condition) untreated in 1, 100 women to study the progress of the disease, without warning them or taking their consent. In at least nine women the lesions progressed to invasive cancer, and 62 women developed localised carcinoma of the cervix before they were treated. The study had been sponsored by the Indian Council for Medical Research, whose function is to

lay down the ethical guidelines for medical research. The investigators said, in their defence, that they did not obtain written consent because most of the women in the study were illiterate and also because written consent was not mandatory when the study was launched (5).

In 1997, the scandal surrounding trials on quinacrine sterilisation forced the Supreme Court of India to step in. Quinacrine was used in the treatment of malaria till it was replaced by better drugs. Some time back there was renewed interest in its use in a method of 'chemical' sterilisation. In June 1994, the WHO Consultation on Female Sterilisation Methods categorically stated that human trials with quinacrine should be stopped forthwith pending the outcome of toxicological studies. In India, quinacrine sterilisation was carried out in the 1990s with "hundreds of doctors involved" according to an early convert to the cause, Dr Biral Mullick. Coordinating the supply of drugs and equipment in the country was Dr J K Jain, former MP. There were widespread protests against these trials. The government of India denied granting approval. Finally, bowing to the public outcry, quinacrine sterilisations were banned by the Drug Technical Advisory Board in 1997 (6).

There is a discernible pattern in all the above instances. All of them pertain to research on contraceptive technologies, reproductive health and vaccine research. More importantly, all of them (except in the case of quinacrine sterilisation) have been conducted in public-funded institutions using public money. They point to the extreme laxity in existing regulatory institutions and mechanisms and also to the tendency of such institutions to submit themselves to pressures when faced with so-called 'national priorities'. Government-sponsored (or -approved) research in India seems to have been fraught with equally potent dangers as corporate funded research is globally.

The anarchy in medical research in the country is typified in three recent examples, only one of which has received some publicity. The last pertains to a clinical trial conducted on human subjects in the Regional Cancer Centre (RCC) in Kerala, with an experimental drug in advanced oral and cervical malignancies. The trials were conducted in collaboration with the Johns Hopkins University in the US. The drug used, M4N, is an active principle of '*chaparral*

tea' made from leaves of the creosote bush, a common American desert plant. Although chaparral tea has been used over the years as an herbal remedy for cancer, it is also known for its toxic effect on the liver. While the trial was conducted in 1999 and 2000, the application for permission to conduct the trials was forwarded to the Drug Controller of India only in February 2001. Further, the Ministry of Health and Welfare states that the RCC was granted permission to import M4N from Johns Hopkins only in February 2, 2001. Apart from these procedural problems it now appears that the trials ignored basic norms regarding informed consent. Further, a preliminary enquiry indicates that subjects enrolled in the trial were given the experimental drug in preference to established treatment regimes, a clear violation of the Declaration of Helsinki on research on human subjects. The trials had not been approved or reviewed by any of Johns Hopkins' institutional review boards concerned with the protection of human subjects, in spite of the Centre's claims that the permission for the trials were granted on the basis of "pre-clinical and other relevant data".

Even more bizarre is the report of a trial of another 'anti-cancer' cure conducted in Calcutta in 2000. The trial was conducted on 24 patients by a team comprising a private medical practitioner and a group of non-medical scientists at the Indian Association for the Cultivation of Science (IACS), a non-clinical organisation. The results of the clinical trial have been published, of all places, in the *Indian Journal of Physics* (7). The journal, coincidentally, is run by the IACS. The paper acknowledges that the trial was conducted through funding from the Council of Scientific and Industrial Research (CSIR) and the department of science and technology and had the approval of the institutional ethics committee of the IACS. Clearly approval was not obtained from any body that is authorised to give such approval. The paper goes on to exhort that "We (authors) sincerely hope that researchers and clinicians with open minds will immediately make a concerted effort to use and to further improve the present formulation and treatment." Worse still, the main ingredient of the drug formulation is a chemical (methylglyoxal) purchased from the American warehouse supplier Sigma Chemical Company, whose chemicals are laboratory grade, not intended to be used as drugs, i.e., they are not biological grade.

The third instance is the permission granted by the Ministry of Health and Family Welfare to conduct trials of the long-acting hormonal contraceptive, Netethisterone Enanthoate (NetEn), in 12 medical college hospitals across the country in 2001. The ministry has not released any details regarding the purpose of the trial or the protocols to be followed. It is being presumed that the trials are a prelude to introduction of NetEn in the country's population control programme. Various health and women's groups have represented to the National Human Rights Commission (NHRC) against conduct of the trials on the grounds that the introduction of NetEn in the mass population control programme is unacceptable given the drug's potential toxicity and the absence of a monitoring mechanism.

What informs medical practice?

There is possibly an even more fundamental conundrum that faces medical research in a country like India. Research output is, as yet, too insignificant and too unfocused to inform the practice of medicine in the country. The latter continues to be largely determined by medical research conducted in the West. This situation has been given a novel twist recently by Dr Samiran Nundy in a letter to the *British Medical Journal*. He argued that given the state of medical research in the country it made more sense to first attempt to regulate medical practice in the country rather than regulate medical research: "That medical research in developing countries is meagre and of generally poor quality is well known, and it has not improved in the past 20 years. Should one therefore discuss research ethics in developing countries when they barely exist? In my view the ethics of medical practice is more important. To see how the public can be safeguarded from an inefficient and often corrupt medical system and receive comprehensive health care of a reasonable quality is paramount." (8)

Such issues arise today because the research institutions in the country have singularly failed to provide any cogent direction to the practice of medicine. It would almost appear as though the two work in entirely different paradigms. Unless there is, at the least, an attempt to marry research with practice, public perception of medical research will continue to range from suspicion to derision.

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Ethical considerations in AIDS vaccine trials

Sanjay Mehendale

Medical research today has several stakeholders across the globe. And the developing world now encourages research done by these countries in collaboration with western governments or pharmaceutical companies. International research poses particular ethical challenges of distributive justice and protection of participants. Such concerns have also arisen in the context of AIDS vaccine trials. Are they testing HIV strains prevalent in developing countries? Will participants who turn positive during the trial receive long-term treatment and care? What are the standards of care that will be provided to the control groups? In this article written before the Indian government launched trials of an HIV vaccine, the author describes the problems anticipated and encountered and the ways to protect research participants.

The Joint United Nations Programme on HIV/AIDS (UNAIDS) estimated (1) at the end of 1998 that around 33.4 million people were living with Human Immunodeficiency Virus (HIV) infection all over the world, over 90 per cent of them in developing countries. However, in developing countries, promising newer therapeutic options for HIV/ AIDS are unaffordable, and prevention through behavioural change has not been successful due to illiteracy and low level of awareness. On the other hand, prophylactic vaccination has shown remarkable success in the control of many communicable diseases. Therefore global efforts are ongoing to develop vaccines (3) to prevent infection among persons exposed to HIV (prophylactic) or prevent HIV-infected persons from progressing to AIDS (therapeutic vaccine).

Present status of AIDS vaccine trials

Developing a safe and effective AIDS vaccine has been a challenge due to a lack of understanding of the correlates of protective immunity to HIV, the absence of an appropriate animal model, strain variation and difficulties in phase 3 evaluation of candidate vaccines (4, 5).

Any new vaccine has to be evaluated at many levels: Phase 1: safety, Phase 2: safety and immunogenicity, Phase 3: large-scale trials for efficacy and Phase 4: post-marketing surveillance. Over 34 different HIV candidate vaccines have been tested in phase 1 trials and three in phase 2 trials (6). Difficulties in initiating large-scale efficacy trials of preventive AIDS vaccines include unanswered ethical issues regarding how such trials would be conducted, fear that trial failure would make successive trials impossible to conduct, and controversy among the scientific community regarding the usefulness of the available vaccines to protect against HIV infection (7).

However, with the continued spread of HIV despite educational efforts, and evidence of the safety and efficacy of many products to elicit immune responses among vaccinees (8, 9), it is increasingly felt that Phase 3 trials of such vaccines are necessary. Therefore, despite an incomplete understanding of HIV pathogenesis and correlates of protection, large Phase 3 efficacy trials have been initiated in the US, Thailand and Uganda (10). Cohorts are also being established, and sites prepared for efficacy trials when appropriate vaccine candidates become available (8).

Deciding when and how to proceed to Phase 3 trials is often complex (6, 11). Some scientists in developing countries are concerned about the deteriorating HIV/ AIDS scenario in their countries and the long time required to complete clinical trials in developed countries. They argue that as the beneficent intent in conducting vaccine trials is clear, trials could be initiated simultaneously in developing countries (12, 13).

There are several reasons to consider conducting trials of AIDS vaccines in developing countries (14, 15). A majority of HIV infections occur in developing countries where an effective vaccine will be most beneficial. The high incidence of HIV infection makes it easier and cost effective to assess trial end-points. It is easier to

assess vaccine efficacy of therapeutic vaccines among HIV-infected people who have not received anti-retroviral therapy. Different routes or co-factors in HIV transmission and the presence of various HIV subtypes may have a differential influence on vaccine protection in developed and developing countries.

To conduct an AIDS vaccine trial, the developing country must have a cohort with defined epidemiologic characteristics, and the technical and scientific capacity to perform clinical procedures and laboratory assays. But such a trial can also raise ethical controversies, as critics, investigators, volunteers, sponsors and regulatory agencies may have conflicting opinions, mandates and expectations. Open communication between the organisations involved and the participating community can minimise this possibility (16).

Trial-related concerns

Participants may fear developing adverse reactions or HIV infection; a post-vaccination positive HIV test result and consequent discrimination; and problems in freedom of travel, insurance, employment and immigration. They may also worry that spouses or partners informed about their trial participation will stigmatise them. The participating community will ask if investigators can ensure adequately informed consent; if trial participants will face discrimination; and if they will receive post-trial benefits. Countries participating in vaccine trials will expect to discuss and approve trial protocols. They will expect that researchers will adhere to the highest scientific and ethical standards, that regulatory bodies will do periodic monitoring, and that the population will get substantial post-trial benefits. Researchers can refer to various international ethical guidelines while planning AIDS vaccine trials (17-20).

Ethical issues in the pre-trial phase

Before selecting a candidate vaccine, and deciding whether or not to initiate a vaccine trial, policy makers, experts and community representatives must have a national discussion on the trial's scientific justification, the clinical and laboratory expertise available and the community feasibility of a vaccine trial. Most current vaccines are based on subtype B of HIV-1.

Testing subtype B-based vaccines in countries where other subtypes are predominant raises ethical questions, though evidence of cross-clade immunity may justify such a trial. Separately, industries in developed countries may not be interested in developing non-B type of AIDS vaccines for countries who cannot buy them. Capacity-building efforts must therefore be made to develop vaccines in developing countries with the help of competent industries in developed countries.

Developing countries may ask if the vaccine has been tested in the country of manufacture. Why should the research be carried out in developing countries? The rationale for conducting the trial must be explained to the community. A network of community-based organisations, people living with AIDS, local medical practitioners, leaders and the media can ensure that the trial is in the community's best interest. It can help disseminate information on the proposed vaccine trials, clear doubts and ensure public support and participation in the proposed trial. Specific cultural, clinical and economic settings influence local ethical expectations and must be addressed while designing field trials (21). Qualitative research should be used to identify the community's fears, so that correct information can be provided in an ongoing manner.

Ethical considerations in an ongoing trial

All the fundamental ethical principles (22) – beneficence, non-maleficence, autonomy and justice – apply to AIDS vaccine trials. For the researchers, this includes ensuring that the study is in the participants' best interests; ensuring that all participants (24) give their informed consent without coercion or inappropriate inducement (19); using comprehensible and informative consent forms and procedures meeting international guidelines and also approved by the Ethical Review Board (ERB); and getting modifications of the protocol and the consent form re-approved by the ERB (23).

Participants should include all groups who may benefit from the vaccine, in particular those with a high incidence of HIV infection. Though children are not included in Phase 1 or 2 vaccine trials, it may be ethically justified to do Phase 2 trials on children (with their guardians' consent) if a therapeutic vaccine shows evidence

of working. Most AIDS vaccine trials will enrol HIV sero-negative persons, which would necessitate a two-step consent procedure with initial consent and counselling for HIV testing and later for trial participation. Respect for local standards such as by taking permission of community leaders does not eliminate the need for individual consent. Investigators must clearly inform trial participants that the vaccine may not work, and provide risk reduction counselling for AIDS prevention. If there is a placebo arm, potential participants must be told about the placebo, and that they could receive either the vaccine or the placebo.

It is absolutely essential to safeguard the confidentiality of trial participants. Researchers' responsibility to maintain confidentiality (with coded forms and samples de-linked from the participants' names) is particularly important in trials relating to HIV/AIDS. Maintaining confidential records may be complicated by the fact that since participants could develop complications in the long term, trial records may have to be preserved for an extended period.

Earlier, randomisation was equated with clinical equipoise – no arm in a trial is known to have an added benefit – making it impossible to test products with some favourable data in randomised clinical trials. This was later revised to suggest that randomisation could be ethical if there were overall uncertainty about the product's utility. Also, in the context of AIDS, behavioural factors and STDs are known to affect HIV transmission and only randomised controlled clinical trials can provide substantive evidence about vaccine efficacy.

Regulatory mechanisms

The Ethical Review Board, which includes experts in pharmacology, pathology, clinical medicine, social science and law (25), should not only review the research proposal but also guarantee that the trial proceeds according to plan and fulfils ethical requirements. The Scientific Advisory Committee's review should cover issues such as the need for the trial, capability and infrastructure at the site, choice of candidate vaccine, methods and appropriateness of selection of subjects, plan for recruitment and retention, mechanism for reporting and management of adverse events and quality control procedures. The Data Safety and

Monitoring Board, which may include some trial participants, should periodically review performance reports, protect participant safety, and define criteria for vaccine or trial failure for which it has the authority to stop the trial. The community advisory board, composed of local workers and community representatives, should liaise between researchers and the community; advise on study procedure and consent and data forms in order to protect the community, play a significant role in community information and education, and help in recruitment and retention of study participants.

The post-trial phase

Once a vaccine is proved to be safe and effective, the vaccine trial sponsors and the host country are morally and ethically obliged to make a commitment for a continued supply of the vaccine in the post-trial phase. The community where the trial was done must either continue to receive the vaccine or be helped to develop the capacity to produce a sustainable supply of the vaccine. This point can be negotiated with the manufacturers before initiating the trial. International agencies can play a major role in this regard (26). Post-marketing studies and surveillance should be undertaken to consider the vaccine's inclusion in ongoing prevention and control programmes.

HIV-uninfected persons considering participation in a prophylactic vaccine trial will be anxious on finding out that as a result of the vaccination, they will always test positive for HIV. This can create problems of discrimination in insurance, travel, jobs and housing. To tackle this problem, those conducting HIV tests for insurance, employment, health care or other reasons should be made aware that HIV vaccines can cause false-positive HIV test results, and trial participants should receive documents confirming their participation in vaccine trials. Social risks and harms to trial participants should be monitored as seriously as physical harms (27).

Some researchers feel that if countries cannot afford to give three-drug therapy to vaccine recipients who develop breakthrough HIV infection, they should not take up HIV vaccine trials. Other researchers from developing countries feel that this is not financially

sustainable; giving the three-drug regimen to vaccine trial participants in a country where it is not otherwise available is unethical because it can be an undue incentive itself. One suggested option is to treat breakthrough infections with two drugs without a protease inhibitor. However, most researchers agree that therapy for breakthrough infections should be given for life and should be on par with the best standards of locally available care. The sponsors and ERB should ensure that such provisions are made and actually followed. However, it might be important to clearly explain to the participants that if they acquire HIV infection and if the vaccine fails, compensation can't be given.

Feedback

Adequate feedback must be given to the community in which the trial was conducted. This could be done through the Community Advisory Board. Effective communication is essential to ensure sustained public support for research.

Conclusion

According to India's Parliamentary Standing Committee on Dreaded Diseases, an estimated eight million people are infected with HIV (28). The Prime Minister has stated that developing an AIDS vaccine is a top national priority. A formal AIDS vaccine development programme in India will probably be implemented through the coordinated effort of the government of India (28). International agencies have stated that they will help strengthen vaccine development capabilities in developing countries (29). These efforts must be supported by advocacy for a clear governmental policy on AIDS vaccine development, identifying and training researchers for vaccine development and evaluation and testing, and public education for future community support to vaccine trials.

AIDS vaccine trials may soon commence in India. While we must ensure that the various codes of research are observed in such trials, research participants' protection ultimately depends on the ethics and commitment of individual investigators (30). Indian researchers should ensure that all future AIDS vaccine trials conform to the highest ethical standards.

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Ethical and methodological conflicts in sexuality research

Leena Abraham

Ethical discussions in biomedical research are based on a fairly well-established understanding of benefit and harm. Social science research in health raises new questions of what constitutes harm. Newer areas such as sexuality research are particularly complex and concepts such as stigma and confidentiality are of critical importance. Research on sexuality frequently focuses on vulnerable adolescents who are in unequal relationships within their families as well as in educational institutions. Here, a researcher explores some of these issues while describing her experience of conducting a study on sexuality among college students, with equally young investigators. Social science researchers are attempting to devise their own equivalent of 'post-trial benefits' to participants.

This essay is based on issues relating to a study of sexuality among low-income college students in Mumbai. Low-income students were made the focus because existing urban studies are on English-speaking students in 'elite' colleges; sex education programmes had not really started in 'non-elite' colleges, and these students' behaviour could be affected by their lack of resources. Data were collected during 1996-1998, from four colleges catering to low-income students in the city. Boys and girls in the 11th standard in high school and in third-year undergraduate college were interviewed. In the first phase, qualitative data were gathered using 10 focus group discussions and interviews with 87 students. This was used to design a survey which used a self-administered questionnaire. A total of 966 students participated in the survey.

A novice in sexuality research may not seriously consider the ethical dimensions of such an enquiry. S/he is usually more concerned about conceptualising the study, choosing the appropriate

methodology and working out the logistics involved in executing the study. The question that haunts the researcher is: "Will people talk about their sexual experiences, especially about taboos such as premarital sex?"

Having no prior experience in such research, I, too was troubled by this question when starting off, but I was not unduly worried because sexual experiences were only one part of my study which was meant to explore a range of issues related to sexuality – sexual socialisation, knowledge and attitudes to sex, peer socialisation, erotic exposure and so on. I reassured myself that if people did not share their sexual experiences with me, I still would have a lot of useful data to analyse. Besides, the refusal to respond tells you whether a group is willing to disclose personal information. It can also tell us the strengths and weaknesses of methodologies for sexuality research.

A review of existing sexual behaviour studies showed that a percentage of young people report pre-marital sex and that more young men report pre-marital sex than young women. Some authors attributed this gender difference to over-reporting by boys and under-reporting by girls, but did not state the evidence for this belief. They apparently assumed that girls refrained from admitting pre-marital sex, fearing the possible negative consequences of such a disclosure. On the basis of my study, I now believe that fewer girls than boys actually engage in pre-marital sex, in order to avoid various negative consequences: a 'bad name' for themselves and their families, the possibility of future marital discord and domestic violence, and so on. While one must be aware of the possibility of over-reporting and under-reporting, it may be best to base one's beliefs on sufficient evidence. At the beginning of the study, therefore, I was mainly concerned about the methodological aspects of gathering reliable data, and how to gain students' confidence and trust. However, I was not fully prepared for the consequences of people disclosing their personal experiences. While methodological aspects of the research were considered in detail, the ethical aspects were considered only briefly. This has changed in the last five years. Sexuality research has tackled many methodological issues and is now discussing ethical dimensions

more seriously. Our experiences may be useful to ongoing discussions.

The research team's concerns

Our first concern was to deal with the methodological and ethical problems at our end: Are we comfortable asking those questions? Is our language appropriate? What are our prejudices? Are we sensitive to young respondents' anxieties? How much should we probe into their lives? Working on these was a protracted exercise.

The research team consisted of young men and women just out of postgraduate or undergraduate courses – almost a sub-sample of our study sample, similarly biased and ill informed on sex and sexuality. But they were very enthusiastic and, above all, well informed about the social and cultural milieu in which the study was located. Prior to data collection we had meetings on the objectives, methodologies and logistics of the study. We spent considerable time talking about sex and sexuality, clarifying misconceptions and filling in information gaps. We also held a two-day workshop on conducting group discussions, interview techniques and note-taking and transcribing. The only ethical issue that the workshop resource people discussed was to 'respect' and be 'sensitive' to the respondent's views. More detailed discussion on ethical issues should have been an integral part of that workshop.

The returns of research

Although ethical issues were not at the forefront of our research concerns, they kept cropping up. During our meetings, research staff raised the question of appropriateness of our research. They perceived it as a one-sided relationship in which respondents 'give' and the researchers 'take'. "Are we providing them nothing in return?" they asked.

In the tradition of social science research that I was trained in, researchers did not provide anything in return to respondents. The returns of research were not perceived in terms of their immediate benefits. Benefits accruing from such research would result from a lengthy process: research findings would enhance our understanding of society, which circulates to benefit the whole group. In other

words, the job of the researcher is to generate critical 'knowledge' that has some value for society as a whole.

Such arguments were not acceptable to my young staff. They raised several questions: "Why should people spend their time and put themselves at risk talking to you if you are not going to give them anything in return?" "Is it morally correct?" "It is only natural that they expect something from you."

Intervention research

Looking for a solution to this dilemma, I came across several research protocols prepared by international agencies in the area of health research, advocating what they call an "intervention component" as part of the study itself. This intervention could be by way of services provided after the completion of the study, or basic services such as health care, counselling, awareness programmes or information, education and communication materials provided during the study itself.

Our study was one of four studies on adolescent sexuality in India, funded by Rockefeller Foundation. The others were conducted by agencies already providing services, for whom the studies were to feed into their services, making 'intervention' the overall aim. Our study was to generate understanding that would feed into programmes organised by various agencies, both government and non-governmental, for youth groups, especially school- or college-based programmes.

The intervention component is increasingly becoming part of research conducted outside traditional social science research institutions such as universities and special centres. I believe that this 'new perspective in research' arose in the context of two developments. First, voices were raised against the use of the bulk of research funds on researchers' comforts even as the respondents lived in abject poverty or in stigmatised conditions. Second, as non-governmental organisations (NGOs) became increasingly involved in research, some of them criticised 'ivory tower' research in favour of more humane research that took into account some of respondents' immediate needs. My gut feeling was that this trend of having a built-in intervention has more to do with the politics of large international funding for research in poor countries. While

this approach seems logical and also reflects some ethical concerns, I am not sure of its methodological appropriateness or its resolution of ethical issues. Could it amount to an inducement to participate? And could the anticipation of a reward, however small, alter the nature of data? I am still not sure.

Social science research has generally held that data gathering should avoid any form of inducement as it can seriously affect the data. However, researchers are expected to intervene in life-threatening situations and other serious crises involving respondents, their immediate families, or the community, and not remain dispassionate observers to document the outcome. It seems ethically correct to provide services to respondents suffering from reproductive tract infections in a study of reproductive health. But what do we do in studies of voting behaviour, or of employment outcomes? Much social science research is seen as a collaborative effort of the researcher and the researched. It is true that research findings often do not get translated into benefits for the respondents. In many cases, no one pays heed to the researcher's findings or the respondents' interests, unless the researcher is backed by influential agencies. However, the 'intervention component' may thwart the efforts of small-budget studies carried out by individuals in lesser-known institutions. Is this a way to make 'ivory tower' research redundant, and to promote NGO research? (Of course, I do not hold that all institution-based research is relevant and I do believe that some NGOs are doing very useful research.) The intervention component is particularly characteristic of large projects. By now we also know that conditionalities (hidden or explicit) are attached to large-scale funding, whether for development projects or research.

A related question is: how is intervention designed? Do we ask the respondents what they need, or do we decide what to give? What if they really need something which we cannot give? What if there are conflicting demands? What if most respondents are not particularly concerned about the rewards? Such issues in sociological research on sexuality become difficult to resolve, while it may be easier to do in a more specific health research project.

After much discussion within the group we decided that we would try "to do something for the students," based on our financial and other capacities as well as students' demands. In order not to let it influence respondents' decisions to participate, we decided not to announce any intervention but informed those who asked about it. The study's returns may not benefit all respondents equally – or for that matter any of them. However, it may have more significant indirect effects. To illustrate, we were surprised when the principal of one of the colleges was quick to grant permission to conduct the study. Later, he mentioned that an unmarried student who became pregnant had been dismissed from the college at the management's behest, an action he felt was unfair to the student. He felt sex education could help prevent unwanted pregnancies but needed concrete findings to convince the management of its need. Here, we saw some benefits accruing from our study, perhaps not to the participants specifically but to the students in general. After the study, our efforts have been to communicate the findings to parents at large, educators and other agencies, in the hope that it will benefit young people. One organisation finds the study useful in its programmes for youth in a rural setting. These issues of benefits and relevance need to be brought to the centre of social research, particularly because of the blurred boundaries between types of research – market research, action research, intervention research, theoretical research and so on. The agencies and players in these types of research have different agendas and objectives.

We tried to meet an obligation to give back to the community in different ways. Wherever possible, we tried to provide information on specific topics, and specific services to those respondents who asked for them. We also asked the students if they wanted a programme organised for them and, if so, what the content should be. Some wanted a meeting with an outside expert to answer their personal queries. This was arranged and the students seem to have found it useful.

Confidentiality

It was not difficult to convince the research staff of the importance of data confidentiality and protecting respondents' identity, but I soon realised that this was not enough. Most research reports only

state that confidentiality of the data was assured but do not speak of how they did this. I realised that these young researchers were discussing "interesting details" with their peers and family members and disclosing the identity of the college. At the same time, college authorities were pressurising them to divulge the names of other colleges where the study was being conducted and the staff felt it was okay to share the information between colleges. 'Leakages' occurred despite many efforts, particularly in the initial stages of the study till the staff became habituated to "guard it as a secret." It was also difficult to ensure that trained staff who leave the study for better jobs continue to maintain confidentiality.

Respondents' identities were easier to maintain as we did not ask their names and their interviews were linked only to a code number. However, another problem arose here: after the transcriptions, I needed more information in some cases but could not go back to gather it. In an exploratory study, unanticipated responses come up which need to be followed up.

Informed consent

This seemingly straightforward ethical requirement turned out to difficult to implement. One practice suggested for literate populations is to obtain respondents' signatures on informed consent forms. Our research population consisted of highly literate college students (16-22 years), but getting their signatures on consent letters seemed to go against our assurance of protecting their identities. The most convincing way we could assure protection of their identities was by not recording their names anywhere. Instead, informed consent was operationalised as follows: In order to recruit students for focus group discussions, members of the research team addressed classes, informing them about the study's objectives and our organisation. A meeting was announced for those willing to participate in the discussions. On the appointed day, many students did not turn up: the reasons given by those present were that some changed their minds, some were absent, and some were not free. We restated the purpose of research and who we were, and how we would maintain confidentiality. We said if they wished to discontinue, they could do so. We began the group discussions a few days later, by which time some more students had dropped

out. Once the group discussions began, the participants stayed on through the multiple sessions conducted with each group.

This two-layered recruiting procedure may have helped ensure the ethical requirement of informed consent. But from a sociological angle, I would have been equally interested in talking to those who wished to stay away from the discussions. Such a self-recruitment procedure is methodologically weak, as it tends to leave out important groups, compromising the validity of data. The objective of an exploratory study is to arrive at a general understanding of the issue, for which it is important to have as many diverse experiences and representations as possible.

Similarly, in individual interviews and in the survey, students were informed of the survey's objectives and nature, the confidentiality of the data gathered and also about us. Their willingness to participate was taken as their consent. However, some of those interviewed did not wish to answer some of the questions and they were not probed. Then, in the self-administered questionnaire, students chose not to respond to some of the questions, and 'no response' was recorded in these cases. On the whole, once they opted to participate the 'no response' rate was low.

Looking back, I wonder if our over-enthusiasm to ensure that the students' participation was completely voluntary ('choice' is something which they are not used to in an institutional context) actually provoked some students' curiosity and generated peer pressure leading to their participation. Some students asked to be included in the study as their friends had been interviewed. Does this violate the rule of 'informed consent'? There could also have been herd behaviour: "Others are doing it, so I must do it too..." Our understanding is that these young people are not used to being given choices. Once college authorities permit an activity by an external agency, it is expected that students cooperate. Of course, students do subvert authority. Besides, any activity that is not compulsory is generally not seen as an important activity by students. Even before we talked about the study, many asked, "Is it compulsory?" Some lost interest when told it was voluntary. The value of 'voluntarism' was obviously in conflict with the culture of authoritarianism in our educational institutions.

Recently, someone asked me how consent was obtained from students under the age of 18. I had not thought about it in such strict legal terms. All were treated equally except that younger (high school) students were given a more detailed explanation.

Should we have intervened?

There were two instances when girl respondents refused to answer questions of sexual experience, in a manner which suggested that they had traumatic experiences. The interviewer respected their 'choice' and merely recorded her observations. Later, we wondered whether we should have probed further and at least offered to help them. As a researcher, I felt that we should have made efforts to collect more sensitive information. Perhaps neither an institutional setting like a college nor a family setting is a suitable location for such data gathering.

Conclusion

Looking back, I feel that important ethical and methodological issues are meshed together especially in areas such as sexuality research. Attempts to protect individual rights may compromise the quality of information, and vice versa. How do we deal with such issues? They cannot be dealt with separately, but should become part of methodological training and debates in social sciences.

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Role of ethics committees in medical research

D S Shrotri

Institutional review boards (IRBs) or ethics committees are a relatively new phenomenon in India. Their role is becoming crucial in the supervision of medical research. The author presents a concise summary of best practices that would enable IRBs to function effectively.

Having worked on the institutional review boards (IRBs, also known as ethics committees) of some institutes, I have a few comments to make on their role in research planning.

Every research institute should formulate a policy statement that should be made available to the IRB. It should mention the type of research it will undertake, such as: pre-clinical toxicology, animal studies in pharmacology or pathology, epidemiological surveys, clinical trials involving patients and studies using healthy volunteers, depending on its resources and infrastructure. This will help in deciding the types of studies to be avoided. The purpose of research – the benefits to be expected from the point of view of its staff, clients, students, society in general or the local community and the institute itself – should be revealed in this policy.

Every research protocol should be scrutinised and cleared by a scientific advisory committee before it is presented to the IRB. Proposals from abroad should have been scrutinised and cleared by an academic body in that country. The local committee may suggest modifications to suit local conditions.

The IRB is not expected to examine the technical details and statistical design in depth. It considers mainly the interests of research subjects. Participating research workers, clinical and para-clinical staff, administrative staff and the institute as a whole may also be objects of its review to some extent. Taking into consideration the source of funding, study objectives, and the welfare and rights of volunteers, patients or (in animal research)

animals, the IRB can suggest suitable modifications to the plan or reject it totally.

The IRB should approve the information and consent forms to be presented to the patients or volunteers recruited for the study. These documents should be in simple language and contain no inducements.

Approval of the IRB should be for a specific period of time, during which the researcher is expected to report to the IRB the occurrence of any unexpected adverse events, difficulties encountered in the work and the progress of the work in general. The IRB has the right to stop the study, modify the protocol or deny further extension of the initial approval if it thinks that the study is not proceeding satisfactorily. For an imported project, guidelines provided by agencies responsible for the protection of rights in the parent country will be useful in continuing the review.

Data obtained during the course of the study, the results of data analysis and conclusions drawn from these results are important concerns from the points of access, custody, ownership, secrecy and publicity. These must be clarified in the research proposal. The IRB must insist that the funding agency or the sponsor will have no access to raw data and individual records. They will be submitted a report in a format similar to that of a paper sent for publication. Interim reports of progress of work may be given for release of instalments of grants. The final analysis should always be made by an academic institute.

The identities of the patients or volunteers must be guarded in most studies. If leftover biological material is to be preserved and used in another study, informed consent forms must mention this possibility. The protocol should also clarify whether the individuals will receive the results of investigations performed on them either immediately or after a period.

The institute and the IRB should insist that the study results are quoted only in scientific literature or technical reports submitted to regulatory authorities and not used for media publicity aimed at the lay public.

The working of the IRB involves extensive documentation. A properly designed research project is educative from the point of

view of record keeping, which proves useful to the researcher in the long run.

To conclude, one must understand that the IRB is an important tool that can be used to put into practice the concern expressed by the medical profession about medical research nearly 40 years ago in 1964 in Helsinki, and which continues to be expressed to cover a wider field.

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Fraud in medical research

Stephen Lock

Researchers don't to talk about scientific fraud, but there is no doubt that it is widely prevalent, with serious consequences for medical practice. The writer gives a short history of scientific fraud and then discusses why it happens and what needs to be done to prevent it.

Introduction

With fraud and sleaze so visible all over the world in politics, finance and public life, finding that these also exist in medical research should come as no surprise. Yet it does, and medical scientists still react as if a case were unique. And they manage it so badly, with the whistle-blower often more penalised than the miscreant (1). Seemingly, fraud has a brief history. I argue that scientists should be aware of the problem, try to deal fairly with any suspected case on well-recognised lines and, crucially, aim at preventing it by following good standards of research practice.

A brief historical account

Most accounts of fraud start in 1974, when William Summerlin purported to show that skin taken from a black mouse could be transplanted into a white one. In fact, Summerlin had used a black-tip felt pen to colour in an ordinary graft of white skin (2).

Nevertheless, fraud has probably always been a feature of scientific work. Some commentators have even accused workers as distinguished as Newton, Mendel and Pasteur of fudging their results (3), while the fact that fraud has featured in at least four novels (from Dorothy L Sayers' *Gaudy Night* [1936] to Carl Djerassi's *Cantor's Dilemma* [1989]), suggests that at the very least it has always been part of the tittle-tattle of senior common rooms.Definition

Should the term be confined to the acknowledged major categories – forgery (the invention of data), plagiarism (stealing the data of others), and piracy (stealing ideas) – or should it include other

abuses such as gift authorship, undeclared conflicts of interest and multiple publication? Some – especially the Nordic countries – see the topic as a spectrum (or a slippery slope) of practices and prefer to talk about "scientific dishonesty" rather than fraud or misconduct, given that there is still no internationally agreed term for the abuse.

In the USA, the central body – first the Office of Scientific Integrity (OSI), and now the Office of Research Integrity (ORI) – wrestled with the problem of definition. Its original statement was unexceptionable until its latter part, which clever defence lawyers could (and did) drive a coach and horses through. This spoke of "other practices that seriously deviate from those that are commonly accepted within the scientific community." What, in particular, were those practices? Did they include, for example, sexual harassment of the supervised by the supervisor? For this reason the ORI set up a special commission to produce a special definition. To many of us the result was a great improvement on the old one, defining misconduct as "significant misbehaviour that improperly appropriates the intellectual property or contribution of others, that intentionally impedes the progress of research, or that risks corrupting the scientific record or compromising the integrity of scientific practices." But the US government rejected this new proposal and hence currently we are stuck with the old one or variations on the theme.

Extent of fraud

The next question – and one that is inevitably raised – is how prevalent is fraud in research? Almost certainly, the cases in the public domain are the tip of an iceberg, but any higher estimates are also likely to be inaccurate. These are derived from two sources: first, surveys of academics for their private knowledge of possible, probable or definite cases and, second, audits of research projects. The first show that anything between a quarter and a half of medical research workers have come across one or more cases, and the second that around 0.25 per cent of research projects are tainted. Furthermore, the list of cases published each quarter by the ORI for one aspect of research alone – that funded by the US National Institutes of Health (NIH) – shows that in each period a consistent

five or six scientists are being found guilty of malpractice. The background to such cases has usually been prestigious. Few of these are lowly workers doing research in minor institutions on mundane topics; instead, the last have comprised the usual range of disciplines and particularly 'hot' fast-moving subjects such as molecular biology, immunology and cancer research. Thus, despite all the publicity, clearly some scientists think that they can get away with fraud. (And perhaps many of them do; we just don't know.)

Causes of fraud

Of the six causes of fraud usually quoted, the first is the pressure on scientists for large-scale publication of positive results to obtain research grants, tenure and promotion. Second comes greed: in some drug trials, particularly, pharmaceutical firms have paid £ 750 or even more for every patient enrolled into a study, and the temptation to invent data for non-existent patients has overwhelmed some less-than-honest doctors. The third cause is vanity – the desire to keep in the swim – and the fourth, though rare, frank mental illness. The fifth is deviancy. As Nobel Laureate Sir Peter Medawar pointed out, every section of the community has a small proportion of crooks and there is no reason why research should be any different (4).

Nevertheless, the most important is what Medawar called the "Messianic complex." In this, the scientist's own conviction that he knows the cause of schizophrenia or cancer overwhelms the normal imperative to do research and obtain the data – which he (and it has usually been a he) then proceeds to invent. This seems to be the reason for the prominent Australian obstetrician William McBride falsifying data showing that emetics given to pregnant animals were teratogenic: one of the first to describe the harm thalidomide did to the human foetus, McBride became convinced that most, if not all, drugs had a similar effect under similar circumstances (3).

Corrective steps

The official approach to misconduct has varied according to the country. The phase of shock/ horror/ denial was succeeded, initially in the USA, by a flurry of reports and recommendations from the

professional bodies, and eventually, after a series of Congressional hearings, by the formation of the OSI. Despite some success, however, this was perceived as ineffectual and liable to frequent legal challenge, and only two years after its creation, it was superseded in May 1992 by the ORI. This reports to a different government department, has a different method of working, and, crucially, sees prevention as equally important as dealing with established cases reported to it (as required for any institution funded by the NIH). Thus it holds regular courses on the ethics of good scientific research, such as the recording and storage of data, the need for regular presentation and audit of data, and good publication practices (including a policy on who is and who is not an author in any individual case).

Such preventive measures are also a feature of the special organisations in the four Nordic countries. Each of these has a central committee on scientific dishonesty, which sees its role as much as for maintaining a high profile for good research practice as for advising on sanctions and instigating investigations with "due process" – the American term covering speed, confidentiality and respect for the rights of the accused and particularly of the whistle-blower.

The USA, the Nordic countries and Austria are unique in having permanent committees devoted to the problem. Other countries – including Australia, Canada and Britain – have produced official reports but have done little to implement them in the way of establishing tangible and long-lasting procedures. Britain, in particular, has relied on its General Medical Council (GMC) to discipline its doctors found guilty of research fraud. The Council has considered the cases of over a dozen general practitioners (though only two consultants), mostly involved in forging data on multi-centre drug trials. They have been admonished, suspended from practice or had their names removed from the medical register altogether. Though such sanctions are severe, the procedure for bringing a case before the GMC is elaborate, while the fact that the case is heard in public on the adversarial basis of English law is enough to deter all but the most committed whistle-blower.

Nevertheless, it would be unfortunate if whistle-blowers were discouraged from carrying out their moral duty in bringing any

legitimate suspicions to official notice. After all, most cases have come to light in this way (with a very few also being disclosed by editorial peer review – though we know that this cannot be relied upon to detect fraudulent work). The ORI commission, which reported on the definition of fraud, also recommended that the whistle-blower's bill of rights should be introduced, similar to that already in operation for civil services disclosures.

Lesson for research workers

They should practise research ethics, not only for their intrinsic goodness but also as an example to others. They should report suspicious conduct to the appropriate authority, insisting that any suspicions be followed to a satisfactory closure. They should ensure that whistle-blowers who raise any questions in good faith are not penalised in any way. They should believe that however rare, misconduct may occur in their own laboratories and that rather than brushing allegations under the carpet, a full and fair inquiry must eventuate.

Those countries that do not have a central committee on research misconduct are, in my view, considerably disadvantaged. Apart from disclosing a cowardice that is usually alien to science, such countries lack several important features of the scientific life: the high profile which a committee gives to good scientific practice (including holding regular courses for trainee researchers); a method for giving the advice and support that both whistle-blowers and local investigating committees need; and a mechanism for collating all the cases in any years, monitoring the action taken and enshrining the details in an annual published report.

Finally, of course, by no means is all medical fraud committed by doctors, in which case other disciplinary mechanisms will have to be devised. At present this is largely limited to dismissal of a non-medical researcher by an employer, but with a code of sanctions laid down by a central body, this would become easier and fairer.

Difficulties there are bound to be, to be sure, in creating some sort of statutory authority which yet has a sure but light-handed touch. But in failing to do so – and, worse, in pretending that either the problem does not exist or can be dealt with on the old-boy network – any establishment is not only selling short its scientific

community but also its population in general, who, through their taxes and contributions to charity, are the true paymasters.

Thus, India, which has a notable tradition of scientific research, should consider what mechanism(s) would best suit its own circumstances. A preliminary attempt might be, as has recently happened in Britain, for funding bodies to give research grants only if they are assured that the institution has in place a mechanism for handling whistle-blowers' complaints with due process.

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Ethics of authorship of scientific papers

R D Ganatra

Researchers writing up their results for publication find that credit must be given to those who do not do any work. The person who did all the work often gets last priority. Technicians are usually excluded from authorship when they are the ones who need it most for career advancement. The author notes that the Vancouver guidelines provide clear norms for authorship: the person should have participated in the conception, design, data collection, analysis, and interpretation, writing and revision of the research and the resulting paper.

Rules governing authorship

My nephew, who works as a research scientist in a reputable medical organisation, asked me: "What were the rules governing authorship of a scientific paper in your time?"

"What do you mean?"

"How did you decide who should be the authors of a scientific paper?"

"There are no rules. You decide by way of convention followed in your institution."

The interval between when I started my research career and when my nephew started his scientific career is about 40 years. It appears to me that the situation regarding authorship of a scientific paper has remained the same over all these years. There are no set guidelines. Each institution has its own traditions. It is still not possible from the list of authors to guess who the real scientific worker is, and who are the supernumeraries.

The Indian experience

It is common experience that if the paper is to be presented in a local conference, the person who has done most of the work would

be the first author and present the paper. If it is a national conference, the head of the division presents the paper and takes credit as first author of the paper. If it is an international conference, the director of the institution presents the paper and hogs the limelight.

The names of the authors on an Indian paper are very often in south Indian style. The name of a south Indian would show his community first and then, in descending order, the names of the village, the grandfather and the father. At the end would be the person's name. The list of authors in an Indian paper follows the same pattern, starting with the director of the institution and going all the way down, the humble scientific worker ending up as the last author of the paper.

Ethical considerations

Are there any ethical considerations involved in deciding the authors of a paper? Are all the authors rightful contributors or is authorship gifted to some? Are all those who have contributed to a scientific project recognised as authors at the time of publication?

All medical research is the collaborative work of a group and multiple authors for a scientific paper is a rule rather than an exception. Who are the persons whose contribution to a project should be recognised by authorship and who are those whose help can be recognised by a mere mention under 'Acknowledgment'? Is the chief of the institution always to be included as an author in all the papers published from an institution?

These questions are important from the ethical viewpoint because the authorship of a paper confers several benefits on the author, the most important being enhancement of the merit for a job or for a promotion. While evaluating candidates, the list of their scientific papers is always taken into account. This list seldom shows the order of names of authors. Few candidates present a list of only those papers where they are the first authors.

International convention prescribes that the principal scientific worker, the person who has done most of the work, should be the first author of a paper. The order of names after the first name depends on the extent of the contribution of each worker to the research project. If at all the director's name is on the paper, it is as the last author.

Gifting authorship

The one who has done the scientific work usually makes a gift of co-authorship with some ulterior motive – continuation of the job, promotion in the job, sponsorship for a fellowship or travel abroad. A gift of authorship is a bribe paid by the real scientific worker because he expects something in return. Acceptance of this gift is an obligation to do something in return.

The practice of putting the name of the head of the institution as co-author is justified by the argument that he was responsible for providing facilities for carrying out research. To promote research is the normal task of any director of a research unit. This justification is also applied for including names as co-authors of heads of clinical units from which patients are drawn for research.

Years ago, I had the following argument with a renowned consultant from whose unit I had obtained patients for liver scan.

"I find that you have published a paper on liver scanning where patients were drawn from my ward."

"Sir, I have put the name of your registrar as co-author of the paper."

"But they were my patients." I was brash and bold then. Moreover, I did not expect anything from that consultant, as I was not an employee of the referring hospital.

"Sir, you have not bothered to look at the reports of the liver scans that I have been sending periodically. You have not even seen the scanner. You have not talked about this procedure to me or to your registrar. All of us know that they become your patients by the fortuitous circumstance of their reporting to the hospital on Monday."

"You will not get any of my patients for your nuclear medicine procedures. I do not wish to see you in my ward in the future."

He was so piqued by this incident that he talked to my chief who castigated me for my insouciant behaviour.

That consultant was so well-known and well-to-do from his private practice that having his name on a paper published in an Indian journal did not make an iota of difference as far as his reputation was concerned but such is the lure of authorship that he craved to see his name on the paper.

As a rebound from this incident, I started putting as my co-authors all those who had really or even remotely helped me in that project, including my technicians and laboratory assistants.

The same chief who had shouted at me in the previous incident called me again. He said, "In this paper where you describe experiments on five rabbits, you have nine authors."

"Yes, Sir. This is because each of them helped me in the conduct of my experiments."

"What is the animal house attendant doing on your scientific paper? The fellow cannot even read English."

"Sir, he got the rabbits for me and helped me in the animal experiments."

"But that is his job. And why did you put my name as a co-author with the animal house attendant?"

"You allowed me to carry out this research project."

Arbitrarily, he removed some names and reduced the list to five – a number identical to the number of experimental animals reported in the paper. The attendant lost his name but my chief did not remove his name.

Authorship of a scientific paper enhances reputations

All heads of institutions have to their credit papers by the hundreds. This is only possible if they allow or force subordinates to put their names as co-authors on all papers published from their institutions. The lure of authorship is so great that many senior scientists accept the "gift" of authorship on papers to which they have contributed nothing. As with all presents, givers often derive some benefit too. If the expectations are higher, the name of the chief is put as a first author. Once one staff member sets this trend, others have to follow.

Vancouver guidelines

The International Committee of Medical Journal Editors (the Vancouver group) drew up criteria for authorship based on the idea that "each author should have participated sufficiently in the work to take public responsibility for the content." (1) In view of this recommendation, many journals go through the ritual of obtaining signatures on the consent form from all the authors. This does not

eliminate the 'gifted' authorship but does ensure that all authors are aware of the names included in the paper.

The Vancouver guidelines suggest that authorship should be based only on substantial contributions to (a) conception and design analysis and interpretation of data (b) drafting the article or revising it critically for important intellectual content and (c) final approval of the version to be published (2).

The guidelines emphasise intellectual contributions and do not include fund raising and supervision of the research group as legitimate justifications for authorship. The guidelines do, however, make it clear that between them the authors must take responsibility for all aspects of the work.

Deficiencies in these guidelines

These guidelines were established to safeguard the position of the editors of journals and are concerned primarily with the written version of a scientific paper. They do not consider how the research project was conducted and who collected experimental data. They ignore technicians who slog to collect the data reported.

The guidelines say nothing about researchers who have contributed to the work but whose names are left out of the paper. It is not easy to build safeguards against this, unless the head of the institution defines responsibilities for the conduct of research projects in advance and closely monitors their progress.

Shapiro et al, in their survey of papers in one American journal, found that 62 of the 1, 176 authors had made no substantial contributions to six major tasks (conception, design, analysis and interpretation, and writing and revision plus collecting data and providing resources), while a further 206 contributed only by providing resources or collecting data (3).

The director of a research institution usually reserves the right to approve what is being published from his institution. It is easy to convert this right of approval into that of participation. Even the guidelines referred to above include "approval right" as a reason for authorship. No staff member grudges the name of the director as a last author if the director at least takes the trouble of going through the paper. Having the name of the director as a first author is carrying things too far.

There are several situations that are peculiar to the Indian scientific scene. There may be a string of intermediate bosses. Are they to be included as authors?

Technicians

Technicians are almost always deprived of authorship. In India, unlike in the West, most technicians are science graduates. It is beneficial for their careers to have their names on as many papers as possible. They work hard to get data from the experiments devised by someone else. They would also like to enhance their merit for a job or for promotion particularly as such opportunities are limited in research institutions. It is an unfortunate fact that this very limitation forces staff members to whom injustice has been done in deciding authorship to remain mute as they cannot leave their jobs.

In research, the most important aspect is conception of an idea and its intellectual nourishment. How are we to decide upon the origin of an idea? Was the idea suggested by your senior or your colleague or by your technician or was it generated during discussions?

Among the technical staff there are two categories: those who participate intelligently and those who carry out assigned tasks in a mediocre manner. Classifying them in this manner is a challenging decision. Usually the primary author does not make such a distinction and includes all his technical staff as co-authors. When you start rewarding mediocrity, you do not know where to stop. Should the laboratory assistants and attendants be included as co-authors?

Electronic media

The problem of electronic media does not affect us, but it will soon. Anybody can put a paper on the internet without any peer review to save the time taken for publication in print. What criteria on authorship will apply here?

Conclusion

There are many ethical questions involved in the simple task of putting the names of the authors on a scientific paper. Are you

putting only those names as co-authors who have genuinely helped in the conduct of your research? Have any names that rightfully belong there been omitted? Answers to these questions are sometimes difficult. No rules or criteria can help. As in all ethical questions, it is more often a matter between your conscience and your common sense, two commodities rather scarce in the medical world.

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STATUE
DEDICATED TO
THE DOCTOR
WHO INTRODUCED
KICK-BACKS
IN MEDICINE

Law, policy and public health

The majority of articles in the early years of the journal look at clinical practice. Issues of the overall health care system, laws and policies are of more recent concern. The selection presented here is eclectic, ranging from orthopaedics to violence. The idea is to go beyond studying issues from an individualistic, practitioner's perspective, to critically examine the role of the medical profession as a part of a system. Thus, a political perspective merges with a traditional ethical perspective, whether it is a humanitarian view of euthanasia or a radical understanding of the medical professional's responsibility in protecting human rights.

This trend distinguishes the evolution of ethics in India. Perhaps this is because ethics has not developed as an academic discipline, but has largely emerged out of practising professionals' reflection and introspection.

The articles discuss issues that have ethical implications for society at large – the use of scarce resources for treatments which have no relevance for the majority, discrimination against patients on the basis of their capacity to pay, the failure of regulatory authorities to ensure a minimum standard of care, the need to evolve a more humane understanding of death and life with dignity, and the role of medical professionals in relation to victims of violence, whether individual or state-sponsored.


BIOLOGICAL
SURROGATE
FOSTER
LEGAL
MOMMY?

Orthopaedics in an unjust world

P K Sethi

In this memorial lecture reproduced in the journal, an orthopaedic surgeon who was responsible for the development of the Jaipur foot raises concerns about the direction taken by the research and practice of this discipline in India. Is it more important to provide care that meets the needs of the poor majority rather than the privileged few? Should technological innovation be driven by local needs or for its own sake? The author stresses that the temptation to opt for a professionally exciting option must not be at the cost of patients' interests. Professionals must imbibe a sense of responsibility for the welfare of the community and develop technical approaches that suit the lifestyle of the people in this country.

Though the discussion is primarily about orthopaedics, this article touches upon various issues relevant to ethics in other medical fields. And while it concerns itself with issues such as consent, equity and justice, there is no reference to the 'jargon' of ethics. This is typical of India, where most discussions on the subject have emerged from experiences and personal dilemmas rather than formal training.

I would like to use this opportunity to talk about the values that Prof Mukhopadhaya has been trying to instil in us and which, I believe, need to be reiterated if we want to practise our specialty to serve the masses of our vast country with its glaring contrasts between the rich and the poor.

I shall not dwell on the personal qualities of Mukhopadhaya, the man. I have already done so in other fora, which bear testimony to the wide sweep of his interests, underscoring the point that an orthopaedic surgeon ought not to be a mere technologist and scientist but a man of culture, understanding our complex social order, the traditions and the belief systems of his patients, our

economic disparities and scant resources. Only then can he serve his patients well, with wisdom and empathy.

When I scan the orthopaedic scenario in our country today, and the direction along which it is moving, I am increasingly baffled. We have been so bewitched by some of the so-called high technology in the western medical world that we are losing sight of the problems which really ought to be of concern, and which are very different from those encountered in affluent western societies. This is making us increasingly irrelevant to the needs of our masses. We have started catering to the needs of our urban rich who believe that whatever is possible in New York or London should be made available to them. The poor get ignored and marginalised. There is a moral and ethical dimension that we cannot ignore. It requires hard work and an intense intellectual effort to try to find our own solutions.

Let us look at what some of our great surgeons did in the past. Mukhopadhaya took it upon himself to work on osteoarticular tuberculosis, pyogenic osteomyelitis, septic arthritis of hip of infancy and adolescence, neglected clubfeet and late and neglected closed and open fractures. In each of these fields he made seminal contributions. A very significant but less widely published concern of his has been post-operative infections. He is one of the few honest surgeons who carefully tried to find out, document and analyse his own post-operative infection rates. I consider this effort to be particularly relevant to the increasingly invasive character Indian orthopaedics is taking today, mimicking the West with a total disregard of the working conditions, teamwork and discipline prevalent in our own hospitals and operating rooms.

Look what Paul Brand did for his leprosy patients and for hand surgery in a modest set-up, Gopal Kini for foot infections and poliomyelitis, N H Antia for facial disfigurement in leprosy, and now Mary Verghese for traumatic paraplegia in our villagers, a tradition continued by Suranjan Bhattacharji at Vellore. Shailendra Bhattacharji's work on post-traumatic stiff elbows is an outstanding example of original treatment of one of the commonest clinical problems we encounter in our country. This is just a small list of a lot of worthwhile work done by surgeons with sheer hard work, perseverance and innovation while working with scant resources.

They have in common an incisive intellect, a sense of commitment and sensitivity to our own problems. Those who lament the lack of financial resources should remember that India produced outstanding scientists in our pre-independence era when there was little funding and facilities for research. The names of C V Raman, J C Bose, Meghnad Saha, Satyen Bose and K S Krishnan come to mind. Nehru built the chain of national research laboratories to provide every available facility, but have we produced any scientists of their calibre? Good work can be done in sheds, garages and basements if there is a will. Affluence often changes priorities and can be counter-productive.

Our problems

I think it is essential for our work to have relevance to our own common problems, to organise an ongoing study of the prevailing orthopaedic conditions in our community. Our personal impressions, based on hospital practice in an urban setting, provide a very skewed picture. Most of us are either indulging in operative fixations of fractures, internal or external, joint replacement surgery, arthroscopic surgery or Ilizarov methods for limb lengthening, corrections of deformities and bone transport – or at least dreaming about them. There is no denying that these procedures have provided us vastly improved methods of treatment in properly selected cases in well equipped hospitals in our large metropolitan towns by experienced surgeons. But Bombay, Calcutta, Madras and Delhi do not represent the Indian reality. A rat race has started among us to ape them, with everyone vying to acquire a superstar status. This leaves behind a large residuum of problems that must be attended to and about which we have stopped thinking. I feel we need to change gears and address ourselves to our common problems and find solutions that can be achieved with our extremely limited resources. For this, we should seek assistance from our epidemiologists, with whom there should be a continuous interaction, as also with our general practitioners and rural doctors. Metropolitan hospitals are full of severe trauma cases and patients requiring elective work find it hard to gain admittance. There is also the very large group which constitutes our office practice, and their pattern has been continuously changing. There is less tolerance

for pain or acceptance of ageing. There is also the fascinating subject of the geography of medicine. Knowing that, and knowing why some conditions are more prevalent in certain territories, would not only help us understand the relative roles of genetic and environmental factors but also lead us to a more rational planning of our services.

I have an impression that the pattern of ailments bringing patients to us is changing. I do not see the classical acute haematogenous pyogenic osteomyelitis in children with the same frequency as earlier. Whether there is an actual decline or whether these infections are being treated at our peripheral centres and do not reach us is difficult to say. Osteoarticular tuberculosis is no longer seen in its earlier classical forms with multiple sinuses and its actual incidence has shown a decline, though it is resurfacing. One often encounters disease patterns modified by ill-conceived drug treatment. I never saw as many congenital dislocations of the hip as I see now. Congenital limb-deficient children are being seen more frequently. Perthes' disease of hip was encountered earlier but was considered insignificant compared to tubercular hips, and we had little to offer by way of treatment. This has become more prominent in our management agenda as our understanding of its radiological classification, the concept of 'head at risk' and the 'containment principle', have emerged. Yet there are cases that cannot be neatly docketed in these classifications. This is why I rate the study of the Manipal group as deserving of more attention. Other centres need to take this up and add to our understanding of the natural history of this condition on a long-term basis.

Congenital clubfoot remains as complex and enigmatic as ever. The increasing frequency of surgical misadventure results in feet getting permanently ruined. Our training of younger surgeons is clearly deficient and we should be allocating more curriculum time to this most commonly encountered congenital deformity.

Poliomyelitis remains the commonest single cause of physical disability, whatever our populist declarations on polio immunisation may claim. The story of polio vaccination is a national scandal, with 'dud' vaccines often being administered. All of us encounter children developing paralytic polio in spite of having had the stipulated doses of oral vaccine. Orthopaedic surgeons should be

documenting such cases to launch a public interest pressure group instead of allowing our politicians and bureaucrats to continuously mislead the public. Lone voices of protest are quickly smothered, as I have personally experienced.

Surgery for poliomyelitis is often so complex and baffling and demands such an intellectual effort that one could make this into a full-time career. Simplistic solutions and camp surgery, which allows no time for meditation and reflection, often do more harm than good. Rational decision-making is not possible without a clearer understanding of biomechanics and locomotion, but we are not teaching these subjects to our postgraduates. We can no longer look for guidance to the West, where this problem is no longer encountered. There is also the great need of preventive medicine in minimising contractures and deformities by spending more time with parents to educate them about simple means of looking after paralysed limbs. It saddens me that most of my younger colleagues are just not interested in the problems posed by poliomyelitis.

Cerebral palsy reaches us more often for treatment – a result possibly of advances in neonatal paediatrics. More brain-damaged children now survive and offer challenges of a most difficult kind. Ill-conceived operative treatment worsens the disability. Heel cords are lengthened with abandon, leading to a worsening of the crouch, an example of how viewing a deformity in isolation can upset the balance in an affliction which is widespread and whose various components are closely inter-related. This is a perfect example of Severid's law: "All problems are results of solutions." Every time we surgically intervene, we should remind ourselves of Severid's law and ask ourselves: "Are we creating new problems for this patient?"

I encounter bilateral idiopathic avascular necrosis of femoral heads far more frequently and am baffled as to its etiology. The known causes – alcoholism, steroids, thalassaemia – are often missing. Many women date the onset following an uncomplicated childbirth. This condition merits a carefully designed multi-centre study and its natural history needs to be followed up. Management is especially tricky for this younger age group and the aggressive intervention often indulged in may be unwise.

Probably the most difficult problem I encounter, and increasingly frequently, is of intractable infections following operative intervention in closed fractures. Indiscriminate use of antibiotics and metallic implants and the phenomenon of bacterial adherence and the glycocalyx responsible for 'cryptic infections' make this a vexing problem to treat. The increasing frequency of interventional treatment, now spread out to even peripheral hospitals that are manned by inexperienced surgeons working in atrocious conditions, is an alarming development. It forces one to concede reluctantly to Ivan Illich's accusation that the modern physician is the most virulent pathogen let loose on mankind.

Lifestyle and culture

Ours is a floor-sitting culture and this places functional demands on our lower limbs, which the chair-sitting culture of the West does not encounter. For us, the lower limbs are not meant merely for standing and walking. They should also be flexible enough to allow us to lower ourselves to the ground for squatting or sitting cross-legged. Our hips and knees have to be supple and our heel cords have to allow the feet to rest squarely on the floor. This is a matter of practice and our soft tissues, muscles and joint capsules get used to this stretching from our childhood.

These functional demands are not permitted in our hip and knee replacements. While joint replacement can serve our urban affluent classes who have switched over to a western lifestyle, it is ruled out for our traditional masses, not only because of its prohibitive cost but also because it would demand a radical change in lifestyle. Now here is a special challenge for us. How do we overcome the two contrasting demands of stability and the required range of mobility? Considering that many of our hip problems result from infection (where a joint replacement may cause a dormant infection to flare up) and most of these patients are in younger age groups, what solutions can we offer? We have to go back to the past, study what an older generation of surgeons did, resurrect some of these procedures and improve on them.

It is curious how squatting as a posture has been frowned upon by most of our orthopaedic surgeons. People with backaches and disc problems are admonished to avoid this position and many of

us believe that this might predispose them to osteoarthritis of the knee. These views have never been, to my knowledge, subjected to any rigorous studies. It is interesting that many western observers advocate squatting as being good for our backs, and Fahrni of Vancouver, studying cross-cultural incidence of backaches, wrote up a monograph extolling the virtues of squatting. I have personally always advocated squatting for my back cases and I am struck by the suppleness of the spine resulting from this practice. Gunn, while working in Singapore, tried to explain the relative rarity of primary osteoarthritis of the hips in Orientals to their habit of sitting cross-legged, which, according to him, allows the femoral heads to be fully contained in the acetabulum.

Quite frankly, do we really have concrete evidence that squatting predisposes to osteoarthritis of knees, as many allege? I know of none.

Let us not condemn outright lifestyle practices that have stood us well in our culture for centuries. What shames me is when outsiders have to remind us of these things and show themselves to be more open-minded than us.

To ask our farmers and housewives to abstain from bending or sitting on the floor seems to me to be irrational and disabling. When I see strapping Jat farmers from neighbouring states consulting me, carrying a metallic lumbar brace, demoralised and defeated, out of work for months or years because they have been warned never to bend, squat or lift, just because they had suffered from lumbago, I have reason to question such prescriptions. In this context, I would strongly recommend a reading of St Clair Strange's presidential address to the Royal Society of Medicine entitled 'Debunking the disc'. I do not know of a more devastating critique of many of our favoured practices for low backache and sciatica. At least let us be aware that there are different ways of thinking amongst some of our most astute clinicians.

Recent trends in Indian orthopaedics

While many of our great teachers took it upon themselves to solve our own problems, the present trend seems to be to look increasingly westwards. Ali Mazrui describes it as submissive dependence. Prof Amulya Reddy derisively labelled it as "blurred Xerox copies" of

work done in the West. Also, like physicians who were brainwashed and bribed by multinational drug companies, described as "pill peddlers" in Donald Gould's book *The medical mafia*, we are now becoming victims of modern marketing strategies of the powerful medical industrial lobby. It offends my sensitivity when I find how our professional conferences and workshops are being hijacked, dominated and controlled by commercial enterprises. I do not quite know who is helping whom.

Abuse of antibiotics

The increasing use of newer and expensive antibiotics to treat infections, without appreciating that bacteria possess mechanisms to mutate into resistant strains, has led to the emergence of Darwinian medicine, which is warning us that our abuse of antibiotics is becoming an ecological threat. Soon our biosphere will have germs against whom future generations will be rendered helpless. Remember also Pasteur's confession on his deathbed: "Germs are nothing. Terrain is everything..." This seed and soil analogy was taught to me years ago by Mukhopadhaya who believed that a good soft tissue cover provided by a vascular flap, along with strategically placed adequate drainage, is an effective treatment for bone infections. This advice has stood me in good stead all these years. I use antibiotics with great restraint.

So-called high technology medicine

The emergence of electronics, digital display systems, microchips and computers is now changing the entire scenario. The extent to which both patients and doctors have become mesmerised by contemporary diagnostic technology is remarkable.

It appears that no doctor is now willing to make a diagnosis and no patient is willing to accept one without recourse to the formidable diagnostic armoury offered by the medical industrial complex. This is leading to amazing distortions. A housewife with a backache now comes to me with a large packet of investigations and tells me she has a 'disc'. When questioned, she pulls out her CT and MRI scans and asks me to see for myself. We have made them forget their language of pain and suffering and started treating images rather than persons. We have stopped being good listeners and have

forgotten the art of communication with our patients, an art which plays such an important role in the equation for recovery. This is what Lewis Thomas called the non-technological function of medicine. Words, said Norman Cousins, can be gate openers or gate slammers. They can open the way to recovery or make a patient tremulous, fearful, dependent and resistant. We can draw out a heroic response or, by using the wrong words, complicate the healing environment. They are no less central in the care of our patients than the factual knowledge that goes into our treatment.

So disturbing has been this obsession for new imaging techniques that the *New England Journal of Medicine* published a whimsical article entitled 'CAT fever'. These have not only put the cost of medicine out of the reach of the poor, but have also led to unethical practices such as kickbacks and often unnecessary surgery. These gadgets possess a 'symbolic value' with very limited 'use value'.

The use of power tools, advances in metallurgy and polymer sciences, fibre optics and image intensifiers has started transforming the scenario inside our operating rooms. The visual impact of these marvels of technological gadgetry literally sweeps us off our feet. The powerful medical industrial enterprise is using all the tricks of modern advertising to push us into buying instrumentation that is obscenely expensive and becomes out of date in no time. We are, conceptually, losing our identity and becoming a mere cog in the wheel, as it were, in this mad rush for mega-technology.

The advances often cited as spectacular in orthopaedics, with total joint replacements currently leading the race, really stem from the fact that we have not understood the basic causal mechanisms of most diseases. We do not know why rheumatoid arthritis destroys joints or why articular cartilage degenerates. So we resort to fire-fighting methods. As a cynic put it, a joint replacement is really an internal amputation, a defeat. Our ignorance exceeds our knowledge. If we understood the basic mechanisms of these diseases, such expensive methods would not be needed.

What we need is more science, not this sophisticated yet profoundly primitive 'half-way technology' which we mistake for high-science medicine. It is in this respect that the biomechanical school, founded by Pauwel, and practised by his followers, offers

joint preservation techniques by well-chosen osteotomies at the hip or knee, which need to be understood and more widely practised.

Let us try to understand the inexorable march of what Fuchs has called "the technological imperative", a tendency to take action – whatever the cost – if it offers even a slight possibility of utility. Einthoven has expounded on what he terms "flat of the curve" medicine – the medical variation of the economic law of diminishing marginal returns as inputs into a system continue to increase. Medicine should consider the possibility of contributing more by doing less.

Treatment of fractures

I am disturbed by the frequency with which, under the influence of the AO school, fractures are being treated by operative fixation. I am disturbed not merely because of an unacceptable incidence of post-operative infections which leads to so much misery, but because of a new kind of colonisation of our minds, aided by subtle marketing strategies, to make us believe that fractures would not unite unless rigidly fixed. The fact, however, is that most fractures unite with perfectly simple and safe conservative measures. I pay tribute to the AO school which has been responsible for elevating the standards of fixation with exquisitely engineered implants in fractures that do require operative fixation. But I question their views on the biology of fracture healing. You would all have encountered the ivory-hard, avascular bone, which is revealed when an AO plate is removed. It is a sorry spectacle when contrasted with the exuberant, almost riotous ensheathing callus reminiscent of a sarcoma that John Charnley illustrated in his thoughtful *Closed treatment of common fractures.* While the AO group has of late been forced to modify its earlier stand, most of us are still struck by its earlier teachings. By the time its new message trickles down to us many patients would have become victim to this fallacy.

The old equation so persuasively taught by our great fracture pundits Bohler and Watson-Jones, that accurate anatomical reduction is equal to good functional result, was effectively challenged by Nicolof Mansfield and George Perkins. Perkins introduced a system of rating fractures: one-star fractures could be treated by any doctor while three-star fractures should only be

tackled by experienced orthopaedic surgeons in a well-equipped hospital. This approach has great merit. His slim text on fractures and his Robert Jones lecture, 'Rest and movement', has great relevance in the Indian situation.

The abominable standards of asepsis in most Indian hospitals does not detract young surgeons from using power tools whose whine so excites their psyche that they behave like adolescents revving up the throttle of a 500 cc motorbike. The scenario reminds one of children playing with toy guns, with the same joyous expression on their faces. 'Fixation is fun' is the title of an editorial written by Apley in the *Journal of Bone and Joint Surgery*. This should be compulsory reading for our residents. Such is the example we set our undergraduates and residents that they have no idea about conservative methods of treating fractures, have never seen a Thomas splint, do not know anything about managing modified Russell traction and have not heard of the Trueta method of closed plaster treatment of open fractures which they would now treat by external fixators.

Let us remember that the bad results of operative treatment of fractures are much worse than the bad results of conservative treatment. We should not be bewitched by our 'best case scenarios' and forget our 'worst case scenarios'. High technology should remind us of the well-known nursery rhyme: "When she was good she was very, very good, but when she was bad, she was horrid."

AO courses on internal fixation at Davos are marvellously organised. It is time for us to conduct similar courses on conservative management of fractures with the same finesse. It will not be easy. The market situation is against such attempts. However, I encounter many bright and idealistic young minds who are capable of taking up such challenges.

Another recent example of how useful advances get misused, aided and abetted by media coverage and our own greed is seen in the use of arthroscopy. Judiciously used, and after spending a long period of apprenticeship under a great master, it is a worthwhile addition to our diagnostic and therapeutic armamentarium. But the recklessness with which arthroscopic clinics are sprouting up like beauty parlours, performing arthroscopic lavages and shaving articular cartilages in osteoarthritic knees, has made our large

population of painful knees captive victims to an outrageously expensive but wholly irrational and meddlesome procedure.

Education of orthopaedic surgeons

I think it has now become our duty to seriously review some of the foregoing distortions that are rapidly invading our profession, and to constantly sensitise our students to concepts of cost-benefit analysis. Economists could be invited to teach them about poverty. There are a number of outstanding doctors who have been working in peripheral areas and who have achieved more than we could achieve under their circumstances. How many of us know of, much less inform our students about, the work of Raj Arole and N H Antia, of Zafrullah Choudhary in Bangladesh or Prawaye Wasi in Thailand? There are activist organisations like Medico Friends Circle who can instil a lot of idealism in our younger generation. Our undergraduates ought to be exposed to them and certainly our continuing education programmes can have a guest lecture each year by some of these. I make this suggestion in all seriousness. This can help restore some awareness about the needs of the bottom 90 per cent of rural and urban poor, instead of the increasing trend to use elitist technologies geared to the demands of the top 10 per cent of our urban elite.

There is an Indian Association of Rural Surgeons. Having attended one of their annual conferences, I was astonished to learn how much can be done in rural areas where none of the trappings of modern urban hospitals are available. We need to exchange notes with them and I am sure this step will be mutually beneficial.

Delegation

Caring for everyone requires that the ordinary tasks of medicine be delegated to the humblest and cheapest member of the team capable of doing it effectively. Such auxiliaries as orthopaedic assistants and rural medical aides need to be trained on a wide scale, to delegate tasks to them and then to supervise them carefully.

Dr Antia is already doing this in the field of plastic surgery and Dr Arole in the practice of rural medicine. Managing the provision of such care is now one of the most critical tasks in medicine. It was said by a professor who started his career teaching

postgraduates, continued it teaching undergraduates and ended it teaching auxiliaries, that he found the last task the most difficult, the most valuable, the most creative and the most rewarding.

I am glad to find that Dr Taneja, with the encouragement of Dr Mukhopadhaya, has started courses in local languages for operating room assistants. Many more areas can be identified for such training programmes which could make our work easier and more effective.

Richard Feynman, the Nobel Prize-winning physicist, spent two years writing a textbook for undergraduates and he felt he learnt more about physics in these two years than in the rest of his career. Hassan Fatthy, the father of modern Egyptian architecture, wrote a gem of a book entitled *Architecture for the poor*. I have been pleading with Prof Mukhopadhaya to write a similar book on orthopaedics for the poor. I am convinced he would find this contribution more challenging, creative and satisfying than all the earlier work he has done.

It is only when one fully understands a subject that one can arrive at simple solutions. Whenever our solutions are complicated, one can take it that the problem has not been understood. It must also be appreciated that technology for the poor cannot either be second-rate or trivial because it invariably poses the tough challenge of having to be what economists call "zero cost." It is a call for "back to basics."

Please remember that our most distinguished economist, Amartya Sen, sitting in the rarefied atmosphere of Harvard or Cambridge, is working on poverty. He is not toeing the line of the World Bank economists bullying India to close public hospitals and hand them over to the corporate sector who would then set up profit-making five-star hospitals with loyalties to shareholders rather than patients.

I end by listing seven axioms worked out by Maurice King in his chapter in the *Oxford Textbook of Medicine* and whose title I have unashamedly borrowed for my lecture. This chapter should be compulsory reading for all doctors to be able to understand the economic consequences of using expensive technologies in a poor country:

'Care for all men.'

'Create a judicious health service delivery system.'

'Teach.'

'Delegate.'
'Apply the most cost-effective technologies.'
'Go widely rather than deeply.'
'Make the community master.'

The main point I have tried to make is that in a dual society such as ours – and this is true of all developing countries – we are constantly confronted by a Hobson's choice. The technologies evolved in the West are preferred by our rich urban elite who really constitute the market forces influencing our decision makers and western-trained professionals The poor are outside the market forces and have no voice. To permit the poor to escape from this dilemma, scientists and technologists must generate new options, each more effective than the traditional and more accessible than the modern. Ideally, the options should constitute a hierarchy of technologies with upward compatibility. Then, with rising incomes, the poor can climb from cheaper options to costlier ones.

Only in such a situation will the people have genuine choices. Thus the role of scientists and technologists is to be option generators and choice-wideners.

A constant reminder of Maurice King's seven axioms would breed equity in our patient care rather than widening the gulf between rich and poor which is what we are currently engaged in. Patient care, after all, means "caring for the patient." I do not want to be misunderstood. I am not advocating a return to the past, to *swadeshi* in an obscurantist or fundamentalist manner. Progress is inevitable and desirable if tempered with wisdom. But what goes on under the garb of progress is often misleading. We have to ask the question squarely: progress for whom and progress for what? We have too many clever surgeons today. What we need to resurrect is that class of wise surgeons who can relate their work to the needs of a very complex society. Surgeons like Prof Mukhopadhaya are rapidly becoming an endangered species. It should be our endeavour to preserve, protect and nurture his heritage.

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The great divide: 'Private' versus 'general' patients

Aabha Nagral

The privatisation boom of the 1990s hit the public health care system hard. For the first time public hospitals in India introduced market-based mechanisms such as "cost recovery." Thus those who could afford to pay did so, and those who could not afford it received treatment free. It sounds good in theory but in fact such a system leads to discrimination and neglect of the poor.

The author describes her experiences in an institution with this dual payment system and argues that creating a dichotomy within the same institution creates dual standards of care. She calls for a system of prioritisation based on medical assessment and not on the paying capacity of the patient.

A less talked-about aspect is the distortion of the patient-provider relationship and its effect on individual patients and even medical training. When doctors behave differently with paying and non-paying patients, they send a strong message to their juniors endorsing existing class prejudices.

The article raises other important questions. How will we ensure equity in a system that is increasingly market-based? How will we inculcate values among professionals in the face of conflicting commercial interests?

Working in a hospital where patients are dichotomised into 'general' or non-paying and 'private' or paying patients brings up some interesting questions and has stimulated my thoughts on this issue. Most hospitals in India belong exclusively to either the private or public sector. Such a stark contrast within one hospital is therefore unique.

Let me illustrate with a typical case history. X is a non-Bombayite, hailing from one of the northern states, who has been referred to

this large hospital in Mumbai. He walks into the hospital accompanied by two relatives from his home town, with a lot of hope, and becomes a general patient. He expresses a wish to meet the doctor to whom he has been referred, and is informed by the junior doctor that consultants see private patients; the best way to get a consultant to see him is to become a private patient.

However, X has been told that the only hope of treating his disease is this hospital, so he holds every doctor he encounters in great awe. He is seen by a junior member of the staff (usually a resident doctor) in the outpatient department, and is asked to get a string of investigations done. So far so good. X's morale is boosted; things are moving in the right direction for him at last.

The process of getting investigations continues much longer than he had expected. Finally he is told that it has been proven that he has a malignancy and needs surgery. What a relief, he thinks to himself. At least he can have the surgery now – but will the senior doctors at least see him once before the surgery? He is once again reminded that they are being consulted, and that they do not have the time to see him as they are busy tending to more important matters.

By now he has a good taste of this discrimination, right from having his blood tested to having an endoscopy performed by the same junior doctor. He has had the privilege of catching a glimpse of the elusive consultant, who does not seem to register his presence at all. He visits the outpatient department once a week to get a date finalised for surgery – it has been three months now. He watches himself withering away; the weekly injections have hastened the worsening of his condition; they seem to be just eyewash to buy some time for surgery.

Along the way, the realisation slowly dawns on him that if he were a private patient he would have been operated upon by now – and it would have been more economical to do so than to live in Bombay with two relatives for more than two months.

He goes to the outpatient department once more – now reduced to half the size he was when he first came to the hospital – and is asked to get the investigations repeated to monitor the disease's progress, since it has been quite some time since he was first assessed. This report shows that the disease has advanced

considerably. He is declared inoperable, given painkillers and sent home.

Contrast this scenario with that of a patient Y with a similar disease, except that he can afford private treatment. He is seen by the consultant the very next day and is investigated completely within a week. In a month's time, he has been operated upon and is on his way to a speedy recovery. The treating doctor tells him he was lucky to have the disease detected early and removed in time.

These illustrations may be extreme examples but are not uncommon occurrences in hospitals with such a dichotomous system. The message is conveyed loud and clear to patients and all those involved in their management: "wealth is health". Of course, one may argue that there is nothing wrong in that. We live in a consumerist society and market principles guide all spheres of life, including medical care. However, is this justifiable?

There are several issues involved in such a dichotomised system of practising medicine. The very act of treating two individuals with a similar disease in a different way goes against the scientific and ethical principles which are supposed to be the guiding forces in the practice of medicine. The practice of wooing the paying patient goes against the professional virtues of honesty, accountability and respect for the patient irrespective of his social status. People will lose all confidence in the doctor when profit is the driving force of medical practice.

This affects medical education and training as well, when such hospitals run teaching programmes and award degrees and diplomas. Doctors who spend most of their day furthering their private practice have little time for formal teaching. Most work done by junior doctors is unsupervised. Consultants rarely see general patients and never perform surgeries or procedures on them. As a result, general patients are always at the mercy of relatively inexperienced junior residents.

When the same consultant who is brusque and busy when walking past patients in the general wards is full of politeness and charm with private patients, it inculcates commercial values in the junior faculty, as they see their role models pandering only to the well-to-do.

Though the proportion of general and private beds and operation tables is supposed to be commensurate with the number of patients seen in such hospitals, this fair distribution is not strictly enforced. The waiting period for a definitive procedure like surgery therefore is not the same for paying and non-paying patients.

I recently had the opportunity to observe paying and non-paying patients under the same roof during a year's stint at a liver transplantation unit in the UK. The waiting lists of patients needing a liver transplant were prepared according to their medical urgency, not their payment status. This practice was strictly monitored and enforced. In fact, private paying patients from abroad were at the bottom of the waiting list, and in a sense transplanted last.

It can be argued that it is difficult to ensure an equitable distribution of health services unless we have some form of socialised medicine. Also, in predominantly private hospitals the few general beds are rarely accessible to poor patients since they are being used by private patients.

One could argue that the private patient who is paying heavily for his health care deserves the best – better than another who pays less or does not pay at all. And educational institutions depend by and large on paying patients for their resources. Finally, the very survival of several such institutes depends on the paying patients. The relatively higher costs of treating the poor, and the possibly lower success rates, create a conflict between the cost-effective allocation of limited resources and the ethical practice of medicine.

The solution needs far-reaching changes in the entire medical system as we medical professionals perpetuate the class divide in society in our day-to-day practice. However, rational and ethical principles demand that the following guidelines be enforced.

First, there should be a regular auditing of the number of procedures performed on all patients – general and private – the number of ward/ICU beds occupied, the precise nature of diseases, nature of treatments, waiting periods, and outcomes. A fixed ratio of general to private patients must be enforced, especially when it comes to procedures. Any glaring disparities should be accounted for.

Second, consultant staff must be required to assess all patients at least once before a final decision on the case is made. There should

be a mechanism of direct supervision, by the senior doctors concerned, of the work done by the junior doctors. All hospitals should have a functioning patient redressal forum made up of members of the senior faculty, a social worker, a member of the junior staff and the head of the institution. All such hospitals should be required to hold a minimum number of teaching sessions.

Finally, even if one accepts that the market economy has come to stay, efforts can be made to treat patients on the merit of their disease, not their paying capacity. A more fundamental change can come about only by changing the attitude of senior doctors who serve as role models for the junior staff and help shape the attitudes they will carry for life.

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Patients testing positive for HIV: ethical dilemmas in India

Sunil K Pandya

This article was written at the peak of the AIDS phobia. There was little awareness about the disease but there were extreme reactions of panic, resulting in discrimination against patients who tested positive. There were few standards of care for HIV-positive patients and relatively little mobilisation of opinion, funding and support for the issue.

The writer explores various dimensions of the discrimination faced by such patients, exposing the prejudices of health providers through his narratives. Analysing European laws in the Indian context, he ends with a constructive code of conduct. Today we find that his recommendations, which would have been considered outrageous at the time, have become accepted norms of ethical practice in the country.

Attitude of doctors towards such patients

Persons testing positive for infection by HIV or showing evidence of AIDS provoke revulsion and fear in medical doctors. These reactions stem from the general knowledge that the diagnosis of AIDS is akin to a death sentence and the belief that a positive HIV test is, inevitably, followed by the development of full-blown AIDS. The fact that HIV is commonly contracted through sexual intercourse and anal penetration or addiction to drugs lends added reason for disgust. There is a close parallel between the behaviour of the doctor faced with a patient showing evidence of AIDS and that, till very recently, towards a patient with leprosy.

This illogical fear has made doctors lose sight of some fundamental medical principles:

- Contracting an infection from a patient is the doctor's occupational hazard. The logical step towards avoiding such

infection is to take all the necessary precautions against transfer of infection. It is not logical to treat the patient as an untouchable.

- HIV is a very fragile virus, vulnerable to all the commonly adopted measures for sterilisation and disinfection.
- Transmission of HIV from patient to doctor in the course of medical examination and treatment is rare
- We are witness to individuals testing positive to HIV and continuing to lead normal lives without ever showing any trace of AIDS.
- Tests for HIV are, at times, known to yield false positive results.

A new class of untouchables

For many patients, the ward of a public hospital is the last stopping place on a dismal journey of stigmatisation. Patients with AIDS are driven from their communities by fearful neighbours, pushed from one hospital to another by doctors and staff members reluctant to treat them and, finally, approaching death in the AIDS ward, left virtually to fend for themselves. AIDS patients have become India's new untouchables, to spend their lives being shunned. Like caste untouchables, patients with AIDS are supposedly protected from discrimination by laws, but statutes have counted for little. In 1994, a reporter for *The Statesman* chronicled the death of a 28-year-old fruit seller, Deepak Biswas, in a Calcutta hospital ward. *The Statesman*'s stories told how Biswas had been left for days on sheets stained with blood and how food had been pushed at him from a distance. After he died, weighing 60 pounds, attendants left his body untouched for eight hours in the tropical heat. Finally, the hospital superintendent helped a relative lift the body into a van to be taken to the cremation ground. Later, neighbours pressed Biswas' family to leave their home, saying they might infect the area.

Biswas, typical of many AIDS patients, had been shuttled through four hospitals before arriving at the AIDS ward. At the School for Tropical Medicine, the main AIDS advisory centre for the government of West Bengal, doctors told Biswas' relatives there was "no seat" for him (1). They referred him to a doctor specialising in India's traditional herbal medicine, telling the family that in a case of incurable disease, "We can use any drug or any measure."

There are also the cases of pregnant women with HIV who have gone from doctor to doctor seeking somebody to deliver their children.

Making the diagnosis

We are witness to several unethical practices in checking for the presence of infection by HIV in our patients:

- Doctors and medical institutions refuse to accept patients for investigation of therapy unless they undergo tests for infection by HIV.
- Tests, ELISA, blot tests are ordered without the patient's informed consent and with no attempt at explaining to the patient or the family the implications of a positive result. These steps are blatant violations of ethical norms. The General Medical Council of Great Britain has, for instance, made a specific ruling: "The Council believes that the principle (of consent to investigation) should apply generally, but that it is particularly important in the case of testing for HIV infection, not because the condition is of a different kind from other infections but because of the possible serious social and financial consequences which may ensure for the patient from the mere fact of having been tested for the condition. Only in the most exceptional circumstances, where it is not possible for the prior consent of the patient to be obtained, can testing without explicit consent be justified." (2, 3)
- The patient showing a positive result on the test is peremptorily dismissed. If admitted to hospital, he is instantly discharged. In many instances, he is told that the reason for this dismissal is the positive HIV report.
- No attempt is made to break the news gently.
- No attempt is made to counsel the patient and family, confirm the diagnosis by blot tests or other sophisticated means, identify the route of infection and boost the patient's morale by telling him that come what may, the doctor is by his side to help as best as he can.
- On the contrary, the doctor-patient relationship is usually terminated abruptly on receipt of the positive report.

- Citizens of Mumbai recall vividly the sixty-year-old patient at the Bombay Hospital who, when told that he had to leave the hospital as his test for HIV was positive, leaped to his death from its eighth floor (4).

Confidentiality

Respecting the patient's privacy

Once the diagnosis of HIV infection is made in a patient admitted to hospital or nursing home, it is rapidly broadcast to all staff members. The change in their attitude towards him is immediately obvious to the patient.

Some clinics plaster difficult-to-miss placards on the patient's bed informing all and sundry of the patient's HIV status. This is especially tragic when the placard remains in place during the hours when friends and relatives visit patients.

Other clinics print the HIV status in bold letters on the cover page of the patient's case notes, at times underlined in red.

When questioned, doctors and administrators offer the explanation that this measure is taken in order to ensure that everyone "takes the necessary precautions when handling the patient."

Informing the spouse

Since the spouse may contract the disease from her infected husband, how is she to be informed of the very real danger she faces? A recent study makes the consideration of this issue of vital significance.

Fifty-seven per cent of individuals in rural South Africa would not tell their wives about their having contracted sexually transmitted disease. If infected by HIV, 66 per cent would withhold information from their wives. Seventy-one per cent of men would not inform their casual partners about their HIV infection. The same study showed that a majority of women claimed a right to know if a man is infected (5).

There is every reason to believe that a comparable study in India would show similar results. How is this problem tackled in India? There are no clear guidelines on the subject issued by any authoritative agency. Most doctors do not consider this a matter warranting their interference. HIV infection has been diagnosed and the patient sent away. There, for most, the matter ends.

A few concerned groups, notably at the National Institute of Mental Health and Neurological Sciences, have evolved a policy. They counsel each patient known to be infected by HIV, individually. At the end of the session where the diagnosis is conveyed and advice offered on available help and treatment, he is told of the possibility of passing on the infection to his spouse. He is strongly advised to inform the spouse about his HIV status and adopt the unfailing use of a condom during every sexual act. During the next interview he is asked whether the wife has been informed. If the answer is 'yes', he is asked to bring the wife along during the next interview for joint counselling. If the answer is 'no', without any acceptable reason (such as the wife being out of station), he is once again asked to inform the wife. This time he is also told that should he fail to do so, the doctors at the centre will disclose the information to her (6).

This practice has international sanction. As noted by Bayer and Gostin, "What is crucial is the underlying ethical principle that confidentiality, while critical, is not the only ethical value. Indeed, when vulnerable unsuspecting persons are placed at risk it may be imperative to breach confidentiality." (7) They refer to the case Tarasoff v Regents of the University of California in America in 1976, where a central legal doctrine emerged. Under certain circumstances a clinician has an affirmative duty to warn or protect unsuspecting targets of his patient's violent intentions. Several judges in America have held it a duty of physicians to warn family members of the presence of infectious diseases in an individual. "No case to date has criticised a physician's disclosure to make limited, appropriate disclosures of a patient's condition under circumstances in which the patient or others were reasonably at risk but for the disclosure. The legal system appears to encourage physicians to act responsibly by making more, rather then fewer, disclosures of patient confidences under the general public policy that the greater good is served despite intruding upon the patient's privacy." (8)

The Centers for Disease Control and Prevention, Atlanta, Georgia, in their guidelines, are very specific. Patients who are HIV antibody positive should be instructed on how to inform their partners and to refer them for counselling and testing. If they are unwilling to

notify their partners or if it cannot be assured that their partners will seek counselling, physicians or health department personnel should use confidential procedures to assure that the partners are notified (8).

Confidentiality in recording and reporting test results

Public health requirements make it necessary for laboratories to maintain records of positive HIV results. There is no difficulty as long as these records remain confidential documents. Where reporting (to public health authorities) is required by law, it is important to shield the identity of infected individuals from exposure (7).

Law lags behind ethical requirements

"There is no statutory provision regarding consent (in India) for testing. A combined application of the doctrine of unconscionable contracts, Article 14 (Equality Clause) and Article 21 of the Constitution (no person shall be deprived of his or her liberty except by procedure established by law) may help in developing the argument that consent has to be informed and supported by counselling services.

"There is no specific statute providing for confidentiality in India. Section 126 of the Evidence Act protects from disclosure, professional communications between lawyers and their clients. No such provision exists in the case of doctors." (9)

Treatment of the patient testing positive for HIV

Several centres avoid all problems concerning the treatment of such patients by turning the patient away. "Doctors in India have refused to treat HIV and AIDS patients in some institutions including the All India Institute of Medical Sciences, the premier public medical institute in India." (8)

Where the patient is not turned away, he is made acutely conscious of the fact that he harbours an illness that is terrifying. Attendants do their best not to make any physical contact whatsoever. Sponging of the bedridden patient is rarely carried out. When contact is inevitable, the attendant dons gloves, cap, mask and gown. We have witnessed doctors donning shielded goggles, plastic aprons

and other paraphernalia such that they appear ready for a voyage in outer space.

Since doctors display fear and disgust these percolate down the line to the humblest attendant who now tosses the patient's linen and hands his meal to him in such a manner that no contact is made. Snide remarks implying certain knowledge of the means by which the patient acquired the infection are made in the presence of the patient and his family.

It is important to recall the American Medical Association Code of 1847 – an assertion that is representative of prevailing international sentiment: "And when pestilence prevails, it is their duty (the duty of doctors) to face the danger and to continue their labors for the alleviation of suffering, *even at the jeopardy of their own lives*." (*emphasis added*)(6).

If contemporary confirmation is required, consider the words of physician-philosopher Edmund Pellegrino: "To refuse to care for AIDS patients, even if the danger were greater than it is, is to abnegate what is essential to being a physician." (10)

The General Medical Council of Great Britain is equally unambiguous: "It is unethical for a registered medical practitioner to refuse treatment or investigation for which there are appropriate facilities, on the ground that the patient suffers, or may suffer, from a condition which could expose the doctor to a personal risk. It is equally unethical for a doctor to withhold treatment from any patient on the basis of a moral judgement that the patient's activities or lifestyle might have contributed to the condition for which treatment was being sought. Unethical behaviour of this kind might raise a question of serious professional misconduct." (2, 3)

Taking advantage of the diagnosis

I know of examples where a patient testing positive for HIV has been charged huge sums for therapy because everything that comes in contact with him during the performance of tests or treatment has to be destroyed. I know of patients who have been charged the full cost of metallic instruments used during surgery when the instruments were carefully cleansed, sterilised and re-used on other patients later.

Patients with AIDS, attending a workshop in Pune, expressed their agony over the dismal state of affairs in the public hospitals in Madras. They encountered corruption, callousness and denial of treatment in these institutions. Death certificates were not issued without the payment of Rs 500 as a bribe at the largest public hospital in Madras (11).

When registered doctors refuse to treat patients testing positive for HIV, quacks take advantage. The workshop in Pune exposed the hollow claims of Majid, a Kerala-based mining engineer, who made extravagant claims about an Ayurvedic potion he had concocted which was said to cure AIDS. A brochure distributed by Majid claims that his drug has the sanction of the Indian Council of Medical Research and the World Health Organisation. People are selling their houses and *mangalsutras* to pay for Majid's drug. Tests by the Indian Institute of Science, Bangalore, showed that this drug contained corticosteroids. It is ironic that while HIV patients had to warn the media against publishing advertisements of his drug and exposed his unfounded claims, the medical profession remaining blissfully unconcerned (12).

Some frequently made arguments and the response to them

I must know whether or not a patient has AIDS. If I know that his test for HIV is positive, I can take appropriate care to ensure that he does not pass his infection on to others.

There can be no argument about the need for a doctor to know all he can about his patient provided such knowledge is obtained in the best interests of the patient. When information is sought merely for the protection of the doctor, or, worse, to the detriment of the interests of the patient (as when he is thrown out of the consulting room or hospital merely because his HIV test is positive), the search for information becomes perverse, unethical and immoral.

I have a life to lead and a family to look after. Why should I involve myself in treating a patient with a fatal, communicable disease?

Such an attitude is born of ignorance and prejudice. HIV is a fragile virus that is easily destroyed. Ordinary precautions taken in the course of the management of any patient are more than sufficient to ensure that the treating physician does not get infected. Despite the hundreds of thousands of documented patients with HIV

infection and AIDS the world over, there are hardly any proven cases of doctors being infected by the virus when the usual precautions were taken.

I have a right to refuse to treat any patient. What is wrong if I refuse to treat a patient with AIDS?

Refusal to treat on the basis of prejudice or fear is not expected of the good doctor. The law does permit any doctor to refuse to treat any patient provided such refusal is not likely to result in irreversible harm or death. By using this provision of the law, the doctor will be acting legally but it will be against all ethical and moral norms.

"There is no specific statute or rules or regulations obliging the doctors to treat HIV patients. However, all doctors and medical personnel have a common law duty to treat patients brought to them."(9)

Some questions that are never answered by doctors

Since you demand that each of your patients gets himself tested for infection by HIV and shows you the result, is it not fair that you get yourself tested for HIV as well and announce the results to each of your patients?

What proof have you that patients can transmit HIV to you? Can you provide references in the medical literature to such transmission?

Since you insist on wearing cap, mask, goggles, gown and special protective shoes, could you provide references in the literature to prove that these are effective in preventing transmission of HIV?

When the literature shows that items used in the care of the patient who tests positive for HIV are easily sterilised by soaking them in bleach and then autoclaving them or sterilising them by glutaraldehyde or ethylene oxide, why do you destroy them?

Why do you charge patients testing positive for HIV more than you would other patients? Where surgery is necessary, why do you charge a patient with HIV more than you do another with diabetic gangrene or peritonitis?

Public health strategy on AIDS

Prevention and treatment

Drugs effective against the AIDS virus (such as AZT or zidovudine) are not freely available to help those infected with HIV. Programmes in India largely consist of advising people how AIDS is contracted, encouraging blood tests and handing out condoms. This is especially regrettable as India is a signatory to the Paris AIDS Summit Declaration (1 December 1994) which rightly states:

"Mindful that HIV/ AIDS prevention and care and support strategies are inseparable, and hence must be an integral component of an effective and comprehensive approach to combating the pandemic, we declare our obligation to act with compassion for and in solidarity with those with HIV or at risk of becoming infected and undertake in our national policies to protect and promote the rights of individuals, in particular those living with or most vulnerable to HIV/ AIDS through the legal and social environment." (13)

Special care centres for AIDS sufferers, or hospices that might allow them to die with dignity, are virtually unknown. As a result, for many AIDS sufferers, the miseries of death are compounded.

The government's failure to set up effective AIDS programmes means that much of the burden falls on private efforts. Those attempting to stem the tide of infection by HIV battle against the taboos of a society that discourages sexual candour, against ancient superstitions that discourage the use of condom use and against indifference, sometimes even hostility, from local officials.

Infected blood

A significant number of commercial blood donors test HIV positive. Although government policy requires hospitals and blood banks to test blood for HIV infection, surveys show that at least 30 per cent of all blood used is not tested, and that this may account for as many as 12 per cent of HIV infections.

The medical profession has failed to take action to prevent tainted blood from entering the blood banks. It was left to social organisations such as Common Cause and the Courts to compel the profession to act.

In an attempt to ensure safer blood supply and lessen malpractice, malfunctioning and corruption in our blood banking system, the Supreme Court told the government to create a national council for blood transfusion. The judges advised the government to enact separate legislation for regulating the collection, processing, storage, distribution, and transportation of blood and the operation of blood banks. The order also called for all of India's blood banks to be licensed within a year. A quarter of them were unlicensed when the order was passed. Other provisions in the judicial order included the ending of professional sale of blood within two years, verifying that trained drug inspectors check the banks, and allowing 100 per cent exemption on income tax to people donating money to the banks. The court's directive came in response to a petition filed by Common Cause.

The court ruled a long while ago. We have yet to see the ruling translated into practice.

Infected semen

At a seminar on medical ethics organised by Max Mueller Bhavan, New Delhi, and the All India Institute of Medical Sciences on October 8 and 9, 1995, a call for caution was sounded in the use of sperm supplied by private sperm banks, which have mushroomed in many cities. Dr Lalita Badhwar, a New Delhi gynaecologist, pointed out that most sperm banks did not test for HIV. Since semen is one of the most potent means for transmitting the virus, this lapse is blatant malpractice.

Research on AIDS: one unwelcome Indian example

This is a story about what happened to 10 people in Mumbai when an American veterinarian came calling with what he said was a miracle cure for AIDS.

These ten, all HIV positive, became guinea pigs in a secret test of an experimental vaccine whose effects, according to international health experts, are still largely unknown. The vaccine based on Bovine Immunodeficiency Virus (BIV) has never been tested on animals and most scientists doubt whether it could offer any remedy to stricken humans. After the trial was abandoned, the patients were left with no medical support (12).

Bhairab Bhattacharya, the Calcutta-born inventor and naturalised American who says he has a PhD in veterinary medicine, was in correspondence with Dr I S Gilada of the Indian Health Organisation. Dr Gilada and a social worker, Maya Gogte, assembled a list of trial participants. Dr Bhattacharya delivered a brief lecture in English about the properties of BIV. Participants were given no printed information about the vaccine and there was no translation for those who spoke only Hindi or Marathi. They signed consent forms, on which it was promised that the clinic would give them follow up medical support. After they received the injection, Dr Gilada handed each participant an envelope containing Rs 1,000. The central government and health authorities in Bombay and the state of Maharashtra say they were deliberately kept in the dark. Dr Bhattacharya argues that the search for a cure for AIDS is too urgent for him to bother with formalities.

The trial was abandoned because of a dispute (between Bhattacharya and Gilada) over money. By the time the second or booster shot was administered on April 12, 1994, the experiment was effectively over. A tenth man who could not be present at the clinic was so desperate to get his shot that he borrowed money for the train fare to New Delhi to track down Dr Bhattacharya. He was shocked to find that they had not heard of Dr Bhattacharya at the addresses where he was supposed to be available. Dr Bhattacharya travelled on to Calcutta where he says he injected four prostitutes who have HIV with the vaccine and distributed milk infected with BIV to several other women in the red light district.

A draft code to be adopted by all doctors

We need to evolve a code of conduct which must be wholeheartedly subscribed to by all doctors. A draft code is offered. This could form the basis for the evolution of a definitive document.

We recognise the following truths:

- The Human Immunodeficiency Virus (HIV) is a virus capable of infecting humans.
- It is a fragile virus that is easily killed by the standard techniques for sterilisation.
- It is commonly transmitted by one person to another through homosexual or heterosexual intercourse, transfusion of infected

blood or blood products, or through unsterile hypodermic needles used for injection into a person already infected by HIV.

- Such transmission of the virus can be avoided by the use of simple measures such as the use of a condom during sexual intercourse, screening of blood donors for HIV and the use of sterile hypodermic needles.
- Infection by HIV produces a chronic, manageable illness.
- We support the rights of infected patients to be treated without prejudice in their workplaces and homes and at health care institutions.
- Some individuals infected by HIV may go on to develop Acquired Immune Deficiency Syndrome (AIDS).
- At present we have no cure for AIDS. The diagnosis of AIDS is, in most cases, tantamount to a death sentence.
- Patients with AIDS may suffer a host of infectious diseases and suffer considerably before they die.
- There is considerable prejudice in many minds against persons known to be infected by HIV or suffering from AIDS. This augments the agony of such individuals.

As aware and concerned physicians, we therefore resolve:

- We are morally obliged and bound by duty to provide the best possible treatment to patients known to harbour HIV or suffer from AIDS, just as we would to any other patient entrusting himself or herself to our care.
- Such care of patients known to harbour HIV or suffering from AIDS will be provided under the umbrella of ethical principles, special care being taken to ensure confidentiality in view of the prevailing general prejudice against such individuals.
- Patients will be offered counsel on the best course of action to prevent transmission of infection to spouses, other sexual partners and the population at large.
- Where the patient is seen to act irresponsibly, we may find it necessary to intervene in the interest of the spouse or the public at large.
- The function of the immune system improves with proper diet, exercise, healthy living and can be assisted by therapeutic means.

We shall do all we can to reduce the possibility of inter current infection and maintain a state of health in such patients.

- We shall discuss scientific knowledge on HIV and AIDS at every forum at our command so as to inform the public, empower it to take measures at preventing the spread of disease and ensure that those infected by HIV have access to the best possible medical care.

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Understanding voluntary euthanasia: a personal perspective

B N Colabawalla

The writer of this essay was an inspiring role model as a physician and also an activist for the concept of death with dignity. This article was written in 1996 but regains importance in the context of recent legal pronouncements on voluntary euthanasia.

This is a systematic analysis of the ethical and moral questions on this subject, exploring both the need for, as well as the dangers of, legalising voluntary euthanasia. The writer also discusses the role of advanced life-prolonging medical technology, raising questions about the quality of life that it sustains and the prolonging of suffering in many instances. A survey of Indian doctors reveals that almost all of them have faced such dilemmas.

Definition

The phenomenal advances in medical science and technology have not been without a significant impact on society. They have brought into relief issues that are altering the pattern of human living and societal values. *Pari passu* with these changes is the upsurge of affirmation of human rights, autonomy and freedom of choice. These issues compel us to re-evaluate our concepts of societal and medical ethics and value systems.

Amongst these issues, one which has assumed global dimensions is the "right to a dignified death" and the related matter of "voluntary euthanasia."

The word 'euthanasia' (derived from the Greek *eu* meaning 'good' and *thanatos* meaning 'death') raises strong emotions and has become controversial as it involves termination of human life that has been unjustifiably equated with 'killing'. Taken singularly the term euthanasia has no practical meaning, and has been qualified

by 'voluntary', 'involuntary' 'non-voluntary' and other prefixes. This presentation will concern itself only with some facets of voluntary euthanasia.

The conceptual definition of voluntary euthanasia is based on a philosophy which embraces humanism and compassion, and one which recognises the autonomy of the individual and his freedom of choice, along with recognition of his dignity as much in the process of dying as in that of living.

Voluntary euthanasia can then be defined as a means chosen by an individual making a request on the basis of a voluntary decision not to have his life prolonged under specific circumstances of ill-health. The operative principles are voluntarism and self-determinism.

There are nonetheless some qualifying clauses to the definition:

- The decision has to be made by a mature adult.
- He (or she) should be in full possession of his (her) decision-making capacity.
- The decision should be made after careful consideration and due deliberation.
- There should be no element of duress or coercion.

The conditions of ill-health must be such as to qualify as irreversible illness which is causing undue pain and suffering and where the terminal event of death is probable in a relatively short period of time.

Complexity of issues

The apparent simplicity of this definition does not however mean that the issues are simple. Albert Einstein once stated: "Everything should be made simple, but not simpler."

Let us consider autonomy and freedom of choice. These are cardinal concepts in any society that professes to embrace liberalism and freedom. Amongst the rights evolved by such a society is the "right to live and die with dignity." Any right of the individual is however subject to the fact that they should not trample upon the rights of others or vitiate societal ethics and values. It is difficult to accept that an individual's decision affecting nobody else except himself either violates anybody's rights or has an impact on societal values.

The freedom of choice though raises one issue-and that is the reasonableness or unreasonableness of the decision and request. In the context of voluntary euthanasia, the reasonableness of the request may be questioned when an individual wishes to have his life terminated in the early stages of even an incurable disease when the quality of life and functional usefulness to the family and society are not severely compromised. One may have to draw a line between the decision made after considerable deliberation and that made on the spur of the moment under stress of acutely distressing circumstances.

Objectives

The primary objective of voluntary euthanasia is the relief of suffering, of which unmitigated pain is probably the most significant component. Pain is a subjective perception and is, at times, very difficult to assess objectively by any scale of measurement. Can we then make a moral judgement on the issue? It may become necessary to accept the patient's assessment because it is only he who can make a judgement on acceptability or otherwise of his pain.

Pain is not the only factor in suffering. One has to take into account mental distress caused by other manifestations of the disease, such as loss of control over bodily functions or loss of cognitive existence, causing a sense of loss of dignity of life. The respect for life and duty to preserve it are concepts of value but they have to be taken in conjunction with the quality of life preserved. We have to differentiate between existence and living. When an individual is no longer able to contribute to his own physical, intellectual and spiritual well being, sustaining such a state is a perversion of the concept of respect for life. Tagore has stated – though in a different context – that we must be made "conscious not of volume but the value of existence." It is a negation of respect for life if mere physical life is maintained at the cost of unmitigated pain and suffering for the individual and the family.

The concept of voluntary euthanasia presupposes that death is inevitable in a relatively short period of time. This period of the process of dying can, now, be extended by technology almost to

the point of absurdity. The question then will be how to judge the end point and who should make such judgements.

The above issues have been posed not to detract in any way from the primacy of the individual's autonomy. They pose some issues of philosophy and moral judgements. A discussion on them is necessary if the procedure of voluntary euthanasia is to be made transparent for general acceptance by society.

Reasons why people opt for voluntary euthanasia:

- Most individuals fear the process of dying rather than the terminal event of death, which they realise is an inevitable end of life.
- They fear the indignity of being hooked on to life support machines and other forms of treatment when all such treatment is futile and death is inevitable
- Under such circumstances they wish to exercise their right to die with dignity. When pain, mental anguish and suffering are only prolonged by such measures, all sensuous existence may have ceased with a loss of personhood.
- The desire not to subject the family to emotional and financial distress when all treatment may be futile.

The Living Will and voluntary euthanasia

In the context of voluntary euthanasia a document variously called the Living Will or Advance Health Directive assumes significance

Some considerations pertaining to the document are mentioned below:

- The directive establishes the individual's legal rights to refusal of any form of treatment offered to him.
- The declaration outlines certain conditions under which he would not like life – or rather the process of dying – prolonged, when all treatment is deemed futile.
- The directive is applicable even when at the critical time the individual may not have decision-making capacity. It specifies that under such circumstances the directive may be taken as the final expression of his wishes.
- The living will should preferably be made out when the individual is in a fit state of health for future consumption.
- The family and personal physician should be made aware of the existence of the declaration.

- The individual has the right to with draw the declaration at any time.

Two other points of significance may be noted. One is that it is always preferable to make out a durable power of attorney to two individuals who can then act in case of the individual not being in a competent state of mind. The other is that, unlike in many other countries, the living will has no legal sanction in India today. This does not detract from its value of establishing the individual's wishes and has a moral force when decisions have to be made at a critical time. In the absence of such a declaration, futile treatment may be continued by the family out of a misplaced sense of duty and by the physician out of a misplaced sense of ethics.

Medical profession *vis-a-vis* voluntary euthanasia

Medical practice today is oriented to a culture that considers that the prime function is to sustain life at whatever cost and irrespective of the quality of life. The physician treats death as an enemy and feels a sense of personal defeat when he fails to avert it. This 'monoculture' of the mind of fighting death, coupled with adherence to outmoded concepts of ethics has led to a mental and emotional block in most physicians towards voluntary euthanasia which is irrationally equated with killing and hence with death. Perhaps the fear of the law and opportunism in society may be contributing to this attitude of mind.

Medical science and technology have produced an impact that calls for re-evaluation of societal and medical ethics and value systems. The prime duty of the medical professional is to relieve suffering and voluntary euthanasia should be viewed in that context. Indeed it is the duty of the physician to treat, heal and offer an acceptable quality of life to a patient. But his duty above all is to relieve suffering by all means available to him. An end point is often reached when death via the medium of voluntary euthanasia is the only 'good medicine'. The physician cannot and should not deny the patient this final wish for relief. The era where physicians knew what is best for patients has long passed. When dealing with irremediable diseases, the choice of the patient – even though it may be for euthanasia – has to be respected.

Some facets of medical ethics in the context of voluntary euthanasia:

- A physician respecting the patient's right to refuse any treatment offered to him, or withholding or withdrawing any treatment considered as futile, or using pain-killing drugs even in doses which may shorten life, is not transgressing any ethical bounds as it is not euthanasia.
- The patient's voluntary and informed consent to accept treatment forms the legal and ethical basis for offering any form of treatment to him.
- Contrariwise, any treatment connected with euthanasia against his desires and consent is unequivocally unethical and immoral.
- As much as the patient has the right to refuse treatment, the physician has a right to refuse participation in the procedure of euthanasia if he has strong conscientious objections.
- A quote from the report of the Institute of Medical Ethics Working Party outlines the ethics of euthanasia. "A doctor, acting in good conscience, is ethically justified in assisting death if the need to relieve intense and unnecessary pain or distress caused by an incurable illness greatly outweighs the benefit to the patient of further prolonging life. This conclusion applies to patients whose wishes on this matter are known to the doctor and should thus be respected as outweighing any contrary opinions expressed by others."

No immutable guidelines can be suggested, as each individual case must be addressed on its own merits. Nonetheless, the requirements as laid out in a ruling of the Nagoya High Court in Japan may be of some aid. They indicate what might be ethically acceptable:

- The patient is suffering from unbearable pain.
- The patient's condition must be terminal with no hope of recovery.
- Euthanasia must be undertaken to relieve suffering. It can only be undertaken at the expressed request of the patient
- A doctor must carry out the procedure. The method must be ethically acceptable.

Role of the physician

The role of the physician in voluntary euthanasia is not only desirable but is almost imperative, as only he can make several vital decisions. This has been summarised by Muller and Hetcher: involvement of a physician at the request of a competent patient is desirable in order to ensure the voluntariness of the request; the incurability of the condition from which the patient is suffering, a caring presence at the time of death and a swift painless death.

Besides the above there is a very controversial area where the physician may be called upon to exercise some philosophical and moral judgement. This area is the one concerning the means used to terminate life. The ongoing debate is between the negative means of allowing death to occur by withholding treatment and the positive means of causing death to occur. The question posed is whether there is a moral difference between the two means. The borderline is certainly blurred when the patient has made a firm request for euthanasia and the terminal event is not far away. It is difficult to see the moral difference between the two when in both the doctor has accepted moral responsibility for the actions taken. As Preston puts it "...it is a delusion to believe we are not terminating life when we withdraw life supports. Will it not be more humane and compassionate to bring about a rapid and forceful end by positive means such as suitable doses of narcotics, rather than prolong the process of dying?"

The above also brings into relief the issue of the 'double effect principle', which often provides a shield for physicians. Once again it is a delusion to believe that we administer drugs, perhaps in increasing doses, to relieve pain and if death occurs thereby it was unintentional. The medical profession should forsake such hypocritical arguments. They must surely know that from time immemorial physicians have used narcotics with a view not only to relieve suffering but also to terminate life.

Attitudes of doctors towards voluntary euthanasia in India

This has not been analysed on a significant scale involving a large cross-section of the profession. Extracts from a sample survey of

200 doctors carried out by the Society for the Right to Die with Dignity in Bombay do offer some indications:

- Ninety per cent stated they had the topic in mind and were concerned.
- Seventy-eight per cent argued that patients should have the right to choose in case of terminal illness.
- Seventy-four per cent believed that artificial life support should not be extended when death is imminent; but only 65 per cent stated that they would withdraw life support.
- Forty-one per cent argued that a living will should be respected. Thirty-one per cent had reservations.
- Considerations involved ethics, morality, law and religion in that order of importance.
- More than 70 per cent were apprehensive of the abuse of the law if one was enacted to legalise voluntary euthanasia.

Voluntary euthanasia and society

The issues of a right to a dignified death and voluntary euthanasia are not the concern of the medical profession alone, and it should not be so if society has to keep a watch over abuse of the concepts. All sections of society must be vitally involved as the issues transcend any philosophical, moral, legal or theological considerations. It is an issue of humanism and compassion. Society will need to change its value systems in the context of the changing medical scenario, of the socio-economic environment, and of the increasing cost of medical services and their cost-effectiveness.

As Spring has stated: "Will we use our knowledge and new power intelligently or will we just adhere to dogmas and beliefs that have no relevance for this age of biological revolution and spectacular medical skills?"

If we have to call ourselves a civilised society we must understand death, respect it and civilise it, as much as we respect life.

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Private hospitals: a case of 'Physician, heal thyself'?

Sunil Nandraj

Access and quality of care are not conventionally discussed as ethical questions, but they are now being recognised as serious ethical problems. This article reflects concerns about the quality of care in private nursing homes which burgeoned in Mumbai from the late 1980s onwards. Hospital care has become increasingly concentrated in the private sector because of the withdrawal or deterioration of services in the public sector. Small nursing homes, to which the article refers, are completely unregulated and are guided purely by the profit motive.

The author starts with the findings of a study on private nursing homes in the city. Irregularities range from violations of norms for physical standards and physical infrastructure to arbitrary fee structures, inadequately trained staff and refusal to provide care. The author discusses the matter of legislation and its efficacy.

Governmental action only after catastrophe has struck

A patient died in a reputed private allopathic hospital in Mumbai after blood of the wrong type was administered during transfusion by a homeopathy doctor. This death led to a Public Interest Litigation (PIL) being filed in the Bombay High Court raising issues with regard to the quality of care provided by private hospitals, the type of staff employed, regulation and monitoring systems and the role of regulating bodies.

Private hospitals neither monitored nor regulated

Till recently only the states of Maharashtra and Delhi had an act for monitoring private hospitals. Due to the pressure brought by various consumer organisations, the states of Tamil Nadu and Bihar

are in the process of enacting legislation. There is opposition by hospital owners and medical associations of the particular states to the proposed legislation.

It is a sad fact that where legislation is already in place, it is not being implemented. It took a PIL to awaken the authorities to implement the provision of the act. The chief justice of the Bombay High Court remarked: "The writ petition has served the purpose of activising the concerned authorities who seem to have woken up and taken certain steps in the direction of implementation of the various provisions of the law."

The Bombay Nursing Home Act of 1949 is quite inadequate in its various provisions. The act is only meant for registration of the private hospital. It does not cover minimum standards to be maintained with regard to space, facilities, staff employed, sanitary conditions, equipment and other supportive services. It is quite surprising and disgraceful that after 50 years of independence, private hospitals and nursing homes are functioning practically unregulated and when regulation is being brought in it is being opposed by vested interests who do not want to be accountable.

This unregulated and unaccountable nature of private hospitals has led to various problems in the delivery of health care. The quality of care provided varies wildly from one such hospital to another. In many cases, there is a lot to be desired.

Statistics on private hospitals not available

The Government of India and those in the states do not have reliable information on the number of private hospitals functioning in the country. According to *Health Information of India, 1992,* brought out by the Central Bureau of Health Intelligence, Ministry of Health, Government of India, there were only 1, 319 private hospitals in Maharashtra. But the Bombay Municipal Corporation alone declared the presence of 907 private hospitals in Mumbai when questioned by the court during the PIL referred to above. Even this figure from Mumbai is an underestimate.

If one was to seek from authorities information on hospitals by size (small nursing homes, medium-sized nursing homes, small hospitals, large hospitals, private teaching hospitals); details on staff and equipment in each; types of cases treated; diagnosis; type

of treatment provided; outcome of treatment; mortality figures and statistical analysis of medical data from each hospital, one would face incredulous, blank visages. Such data are just not available. Worse, since no records are maintained by many of these hospitals, there is no way anyone can ever get such information.

Only in the recent past have attempts been made by researchers and the media to study various aspects of the functioning of private hospitals. These studies have shown a variety of unpleasant facts on the functioning of private hospitals.

Some perturbing findings

A large majority of private hospitals in the country have less than 30 beds and most of them are run by individual proprietors. The number of hospitals that are run by entrepreneurs and corporate houses who appoint doctors and other staff to run the hospital is relatively small.

There is a misconception being perpetuated that private hospitals provide care of good quality. This is not supported by facts. The findings of the various studies conducted on private hospitals show that the condition of many of the private hospitals and the quality of care provided leave a lot to be desired. This is a consequence of the fact that they are not regulated and monitored.

In the premier city of Mumbai, a study showed that 62.5 per cent of the hospitals were located in residential premises and 12.5 per cent were in sheds that had roofs of asbestos or tin. Of the 22 hospitals that were supposed to have operation theatre facilities, only 15 had a designated area for this purpose. In seven hospitals the operation theatre was also used as the labour room. In many hospitals, the operation theatres were located in the kitchen of the flat, with leaking roofs and paint peeling off the walls. In one instance, the operation theatre was located below a toilet block and fluid from the toilet was leaking through the roof into the area where operations were being performed! Seventy-five per cent of the hospitals did not have separate scrubbing and sterilising rooms. Many hospitals were not equipped to handle emergencies and did not have supportive services such as generators (1).

Most private hospitals function with unqualified and inadequate staff. In another study 39 per cent of the hospitals were functioning

without either a full-time doctor or a visiting consultant. Some 29.6 per cent of hospitals were run by non-allopaths but these doctors prescribed allopathic drugs. In 10 per cent of cases, these doctors functioned in isolation. Patients in intensive cardiac units are left to the mercies of homeopaths or ayurveds. In one case a non-allopathic doctor also performed surgical operations using allopathic techniques and drugs.

Only three qualified nurses could be found in the entire sample of 50 hospitals studied. Many doctors boast of the fact that they have trained the 'nurses' who were also assisting them in the operation theatres. When asked why these nurses are not certified by the Nursing Council to ensure adequate training, the doctors remain silent.

With regard to equipment and instruments, too, private hospitals were found to cut corners. An oxygen cylinder was available in only half of the hospitals claiming to provide obstetric and gynaecology services. A labour table was available in only three-fourths of the hospitals, and a suction machine in eight out of 10 of them.

With regard to surgical services, only a third of the hospitals studied had an X-ray machine, half had an oxygen cylinder and a third possessed an electrocautery unit. None of the hospitals had a Boyle's apparatus for conducting general anaesthesia (2).

The sanitary conditions in private hospitals are also appalling. In both the studies quoted above, the hospitals were congested, lacking adequate space, with narrow and crowded passages and entrances, dirty beds, sheets, pillows, insufficient lights and ventilation and lack of privacy for the patients. Catering to a patient who suddenly took a turn for the worse was impossible under these conditions for there was no space around the patient's bed for any intervention and there was no way such a patient could be shifted out immediately for transfer to an intensive care area. The number of toilets and bathrooms were not in adequate proportion to the number of beds provided.

In nearly all the hospitals it was found that the waste disposal was shocking. Most deposited it into the common garbage dump of the locality. There was no segregation of gauze and dressings

soaked by blood or exudates. Sharps were not destroyed before disposal.

If these are the findings in the city of Mumbai and in an average district of Maharashtra, can you imagine the condition of private hospitals in states such as Bihar, Uttar Pradesh, Rajasthan, Orissa and Madhya Pradesh?

Doctors in private hospitals tend to ask for many more tests than are required on clinical grounds and perform unnecessary operations. The Kerala Shashtra Sahitya Parishad study revealed that of the total number of Caesarean deliveries conducted, 70 per cent were performed in private hospitals (3). Tests and cross-consultations are often recommended because of the kickbacks received rather than for the actual diagnosis.

When, however, patients in private hospitals develop complications, they are promptly referred to public hospitals so that the doctors under whom these complications developed are not liable when death follows and their images remain untarnished. Most private hospitals refuse admission to accident cases (even if the accident occurs next to the hospital) and those involving medico-legal work, even when the patient is in a serious state.

Fees

Another major problem related to private hospitals is with regard to the fees charged. There are no restrictions on what is to be charged and no fixed basis for levying such charges. There are no guidelines on fees charged by private hospitals. Fees are often irrationally exorbitant.

Public scrutiny

What, then, needs to be done if these private hospitals are to be forced to attain and maintain a uniformly high standard?

First of all, we need national, enforceable guidelines categorising private hospitals by size and laying down the minimum requirements to be fulfilled by each hospital in each category. These guidelines must encompass standards on location, layout, environment, approaches, architecture, equipment and staff. Stringent guidelines are necessary to ensure that whilst a fair financial return is ensured to the person(s) running the hospital,

fees are charged on the rational basis of a nationally and regionally accepted formula.

Private hospitals from the humblest nursing home upwards must be compelled to publish their balance sheets and statistics on patients treated during each financial year.

Given the dismal state of our body politic, such steps are unlikely to be taken for quite some time. Can anything be done in the meantime?

All aspects of the functioning of private hospitals must attract a closer look by consumers. Citizens must make their demand for regulation of private hospitals in the country heard by those in power.

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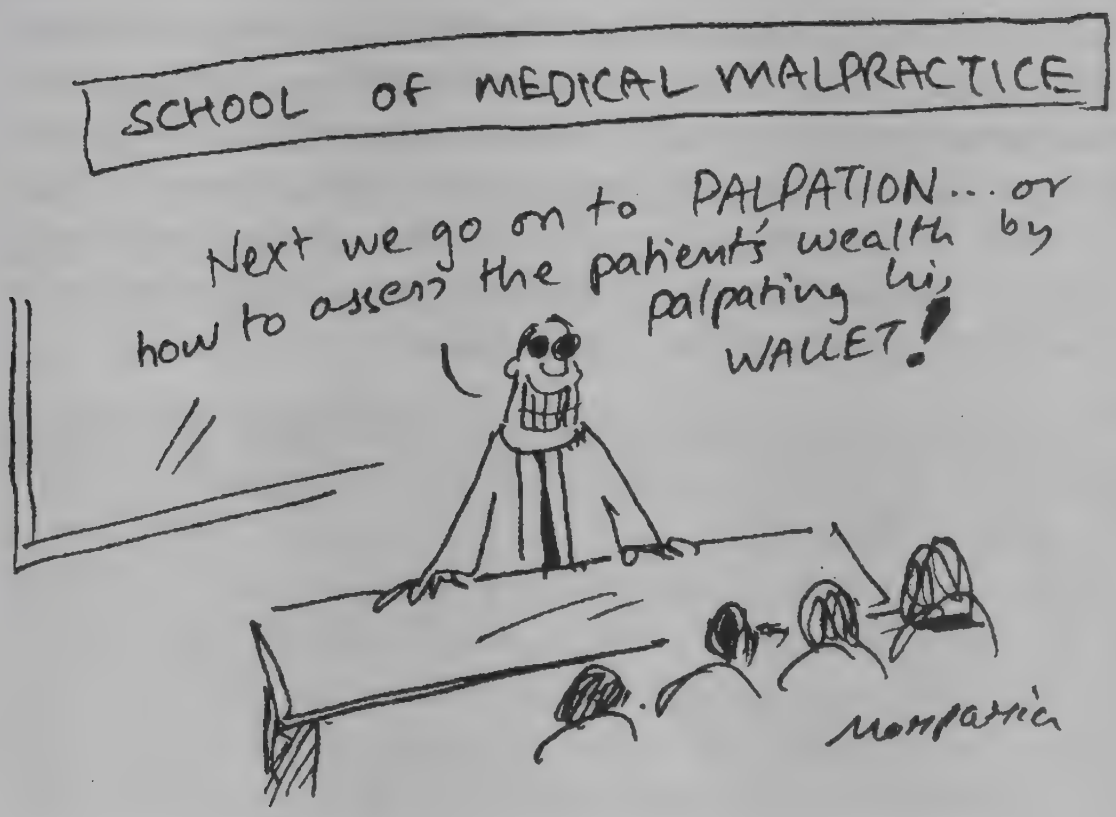
SCHOOL OF MEDICAL MALPRACTICE
Next we go on to PALPATION... or how to assess the patient's wealth by palpating his WALLET!

Violence and the ethical responsibility of the medical profession

Amar Jesani

Doctors regularly see patients who have been victims of violence. Most often, they concern themselves merely with the treatment of injuries, ignoring that these were the result of violence. This attitude is symptomatic of the general reluctance to get involved in matters relating to the state and the law. Moreover, health professionals who are employed by the state become party to such violence or the cover-up of evidence. But the medical profession pays little attention to its responsibilities in this serious issue.

The author deplores the absence of discussion, in medical education, of violence and its medical consequences. He says the medical profession must put professional ethics above administrative orders and actually enforce the code laid down by the Medical Council of India which requires that doctors refrain from participating in or colluding with anything that harms the individual. He suggests that the medical profession adopt standardised international protocols when dealing with cases of violence.

Prof Upendra Baxi, a well-known expert on law and a former vice chancellor of Delhi and South Gujarat universities, in his comments on Women's Studies in the *ICSSR Newsletter* seven years ago, made some incisive and disturbing comments on the coverage of violence in social science discourses in India:

"Mainstream social sciences in India have altogether ignored the fact that India is a very violent society. There do not exist even pre-theoretical discourses on violence in India. Compared with the practice of violence in India, there is a total denial of discourse on violence." (1)

Health care professionals have fared even worse than social scientists.

The concern for violence is conspicuous by its virtual absence in medical discourses. The special medical needs and rehabilitation of victims and survivors of violence are hardly ever discussed by doctors. Is this because health care workers do not come in contact with the victims and survivors of violence? The answer is a categorical "No!". Violence invariably inflicts physical or psychological trauma and in any violence, the victims and survivors come in contact with health care workers, the last and extreme contact being established during autopsies on victims of violence. The apathy of medical personnel is all the more disturbing simply because, of the many professions in our country, medicine has the greatest claim to nobility, compassion, humanity, rationality and scientific attitudes.

Unlike some extremely backward countries, we have nearly a million (9, 27, 624 in 1991) formally trained doctors, 42 per cent of whom are trained in modern medicine (2) – a ratio of one doctor for less than 1,000 persons in the country as a whole and one doctor for less than 500 in the urban areas. An estimated 85 per cent of all trained doctors work in the private sector (3). Yet, the conscious response of the profession to one of the bigger epidemics of violence in recent times in our country has been grossly inadequate. We have either shown plain indifference or clumsy and ad hoc crisis management when faced with violence. This does not auger well for a profession claiming to have scientific basis for its practice. The implied failure in discharging social responsibility raises ethical questions for the profession at large in the country.

Violence and the medical profession

The science of medicine incorporates sociological and epidemiological understanding. Medicine and, for that matter any science that is not geared to real social and epidemiological issues, loses its humanitarian content. The violence described and documented by voluntary groups is not that by common criminals. The violence covered here includes the deprivation of human and democratic rights, is associated with social and political mobilisation, is often inflicted on helpless, oppressed, unarmed or

innocent persons and has notable ideological underpinnings. There are strong, extreme and, sometimes, genuine differences within the social groups on the attitude society should take on the subject. One finds strong defenders (and opponents) of third-degree methods – a euphemism for torture – almost routinely employed by the police. Similar divergence prevails in debates on caste, communal, gender and other forms of violence.

One's social position and ideological orientation, rather than the fact of the violence and the plight of victims and survivors, seem to determine the stand taken on violence. Of course there is also a big segment that has either become emotionally numb from excessive exposure to violence or indifferent, as at present it is not directly affected.

Such trends prevail in the medical profession as well. To what extent is the attitude of doctors to violence shaped by their social positions and ideological orientation? There has been very little research on doctors' attitudes on violence and the extent to which individual biases get reflected in medical practice. Some indication of what is happening at the ground level within the profession is available from the recent reports of various local, national and international groups. These reports were prepared for specific purposes and their findings on the acts of commission and omission cannot and should not be generalised. Nevertheless, they do serve as pointers. The few examples given below on post-mortems and torture and rape are selected by me in order to illustrate issues. I understand that there is always the other side to every story.

Autopsy

The way autopsies are conducted, findings recorded and access to reports denied has been a bone of contention for long. There have been reports in the press about the pressure exerted on doctors by the police to give findings favourable to them. The death of Dayal Singh in police custody made the Resident Doctors' Association of the All India Institute of Medical Sciences (AIIMS) protest against such pressure. This is referred to in Amnesty International's (AI) report titled *Torture, rape and deaths in police custody* (4). The autopsy reports on two nuns murdered in a Bombay suburb, and the role of doctors in unscientific interpretation of its findings,

are also fresh in many minds (5). On study of autopsy reports on victims dying in police custody and on so-called deaths during 'encounters' in the past few years, I found several disturbing issues which have grave implications for the unethical behaviour of doctors conducting autopsies:

Autopsies are generally conducted by police surgeons in police hospitals to which lay people and other doctors have no access. An independent medical audit of work being done there is unheard of. This situation is conducive neither to good science nor to ethics.

A study of autopsy reports (no such study is available, hence the need for it) of victims of violence would probably show incomplete and unscientific documentation. The Supreme Court had to order, in 1989, that all post-mortem examinations held at AIIMS be standardised. On making inquiries I learn that this court order has remained inadequately implemented.

There is a crying need to adopt (with suitable modifications) the United Nations' manual on the effective prevention and investigation of extralegal, arbitrary and summary executions (6). Such routine, standardised and scientific investigation by the medical profession would go a long way in checking arbitrary killings and in upholding medical impartiality and neutrality.

There is also a need to make the whole process more accessible to other doctors and the public. The profession could allow a doctor appointed by the relatives of the deceased to remain present at the autopsy. They should make the official report available to the family doctor and the patient's relatives. This is an issue on which the profession can easily assert its authority.

Torture and rape

There have been numerous official denials that so-called third degree methods of interrogation or torture are practised by our police and security personnel. The evidence accumulated so far does not support such a claim. Some retired police officers, reared in the old school of correct policing, have publicly criticised the "new methods of policing" which condone the use of torture, illegal detention and tampering with records and in worst cases even condone execution of hard-core criminals by police officers (7).

AI's report (1992) cites 13 cases of custody deaths due to torture in the period 1985-89 in Maharashtra. A Bombay newspaper reported a study by the prestigious Karve Institute of Social Work, Pune, giving the toll of custody deaths in Maharashtra in 1980-89 as 155 (8). On inquiry I find that of these 155 deaths, 102 had taken place in the five-year period 1985-89 for which AI had reported only 13. On analysing the causes of the 155 custody deaths, I find that only 9.7 per cent (15 of 155) were admitted as due to police action, 44.5 per cent (69) were attributed to suicide or acts of the accused, seven per cent (11) to acts of the public, 22.6 per cent (35) to disease and illness, 13.6 per cent (21) were termed natural deaths and in 2.6 per cent (four) the cause was not known or records not available. I was astonished to learn some of the specific causes listed: alcohol consumption (nine cases), hanging (45), jumped in well (three), jumped under the train (two), jumped under the autorickshaw (three), jumped under the bus (one), fell from the cot (one), skin disease (one), giddiness (one), unconsciousness (one) and so on. Given the norm that every death in custody ought to be investigated and a proper autopsy done, such causes are not only incomprehensible but also lead to the suspicion that a larger proportion of deaths is due to torture.

In an investigation of death in police custody in Bombay, I, along with two journalists and a lawyer, found that the young victim accused of petty theft was in the course of interrogation brought to the hospital in a serious condition with, as per hospital records, inflicted injuries on his wrists and thighs typical of torture, bloody vomiting, pain in the region around kidney, etc. He was given some treatment and asked to go back to his cell by the doctor. It was also found that the doctor had taken a case history and examined his patient in the presence of the police officer who had accompanied the victim.

The doctor did not consider the presence of the police as violating the doctor-patient relationship. He insisted that he did not suspect torture as the victim never reported it to him. The victim died in his cell.

Similar findings were made by us in an investigation of a victim of gang rape wherein, in spite of the visible signs of injuries around the vagina, which could make any medical person suspect rape,

the male doctor turned away the patient after treating her injuries simply because the woman could not tell him that she was raped (9). The woman had reported rape to the nurse on duty but could not communicate this to the male doctor.

In another case of custodial gang rape and torture of a tribal woman by police in Gujarat, the commission of inquiry constituted by the Supreme Court found that two doctors at the government hospital were guilty of shielding the policemen and issuing a false certificate (10).

These examples only represent the tip of the iceberg. Doctors who come in contact with survivors and victims of violence are not always conscious accomplices in ignoring or covering up the cases. I have been given various reasons for non-reporting and conspicuous silence by medical doctors on torture and rape.

A section of doctors involved are plainly ignorant about this aspect of medical work. If it is true that it never occurs to a doctor that a policeman should not be allowed to remain present during the doctor-patient interaction, or that certain signs and symptoms should make him/ her suspicious of possible torture, it shows crass ignorance in the profession and a grave lacuna in their training.

Another section is indifferent to the plight of the sufferer due to their own social biases against the victims and survivors. Such indifference is also produced by social pressure to conform to the dominant belief. In cases of torture inflicted on persons labelled as terrorists, I have found doctors faithfully treating the injuries of the victims but showing great reluctance in mentioning torture, due to the fear of being seen as opposed to the state's efforts at fighting terrorism and separatism.

A third section simply believes that by being in the employment of the government, the police department or the prison, they are bound by the orders of their superiors and feel that the code of their service does not allow them to "blow the whistle."

The profession has failed to take the unequivocal position that when a doctor has to choose between an administrative order and professional ethics, the latter must prevail. The profession has also failed to protest when doctors are transferred as punishment for criticising gimmicky and unscientific measures taken by the authorities during epidemics, or when security forces harass and

raid hospitals, interfering with the treatment of patients as in Kashmir (11). Such lack of collective assertion of professional independence and neutrality on crucial issues has left individual doctors defenceless, cynical and by default subservient to the authorities.

Another reason for doctors' apathy to these issues is their unwillingness to get involved. Many remark, "We are doctors. We treat illness. We are not interested in torture or rape." This is both inadequate science and poor ethics.

Treatment, rehabilitation and documentation

Recognition of the fact that the reported instances of torture represent only a tip of the iceberg emphasises the need to document the problem in a systematic manner. There is a need to put together experiences in treatment and rehabilitation of such victims, create a clearing house for such information to be disseminated among interested professionals, and thus systematise corrective medical intervention.

This would also provide precious information on the extent of the problem encountered, the individuals and agencies (state, terrorists, armed groups, gangs) involved in torture, the type of people affected, the type of torture methods used and so on. This information in turn would sensitise the profession and make it easier for medical associations and groups to successfully campaign for rooting out conscious or unconscious complicity of doctors in torture or its cover-up. Such information will also sensitise other professionals in the media, law, social work, etc, to play active and meaningful roles in creating public awareness, in punishing the guilty and in rehabilitating survivors.

Code of medical ethics and torture

The code laid down by the Medical Council of India is a good but greatly neglected document. Despite debates about commercialisation and sensational revelations in the press on various allegedly unethical practices by doctors, very little has been done by medical associations to popularise and enforce this code.

Although the principles enunciated in the code are universal and exhort doctors to refrain from participating or colluding in anything

that harms the individual, there is a need to make them specific and directive, particularly in relation to the victims and survivors of violence. This could be easily done by incorporation of the international declaration on the subject in our code.

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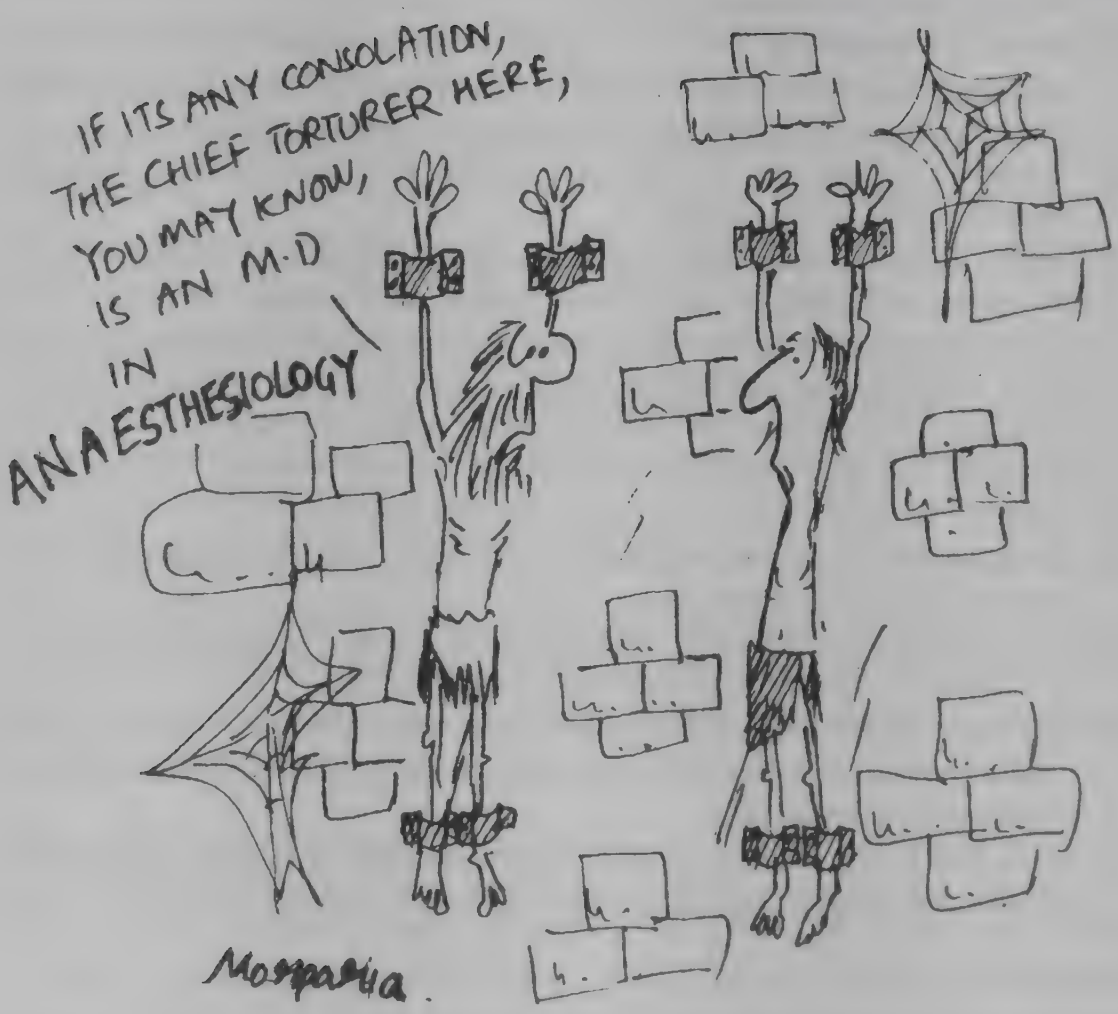
IF ITS ANY CONSOLATION,
THE CHIEF TORTURER HERE,
YOU MAY KNOW,
IS AN M·D
IN
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The Forum for Medical Ethics Society

The Forum for Medical Ethics Society (FMES) was founded in 1994 by a group of health professionals, researchers and activists interested in health care ethics. FMES is a registered body under the Societies Registration Act of 1860.

One of FMES's activities has been the publication of a quarterly journal, *Indian Journal of Medical Ethics* (formerly *Medical Ethics* and then *Issues in Medical Ethics*). Published regularly every quarter since its first issue in August 1993, *IJME* has focussed on ethical issues in health care in India while raising issues relevant to developing countries as a whole.

The Centre for Studies in Ethics and Rights

The Centre for Studies in Ethics and Rights (CSER) is a research and training institution set up by the Anusandhan Trust. CSER was set up in January 2005 to develop research and training programmes in ethics and rights for students, researchers in the social and biomedical sciences, and various professional groups including social workers, medical practitioners, counsellors and lawyers. CSER has organised a number of programmes in collaboration with institutions and individuals interested in the field of bioethics. It has also started publishing collections of papers on ethics, in collaboration with various organisations.

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